



# Brain Tumour

*You are not alone on this journey...*

## Meet Yaron Butterfield:

writer, artist, scientist...  
and 15-year  
glioblastoma  
survivor

### Also inside...

- Barriers to accrual and enrollment in brain tumour trials
- NCI-CONNECT and rare brain tumours
- Report of the Indian Society for Neuro-Oncology (ISNO) annual conference in Bhopal
- How allied healthcare professionals can help
- GLIOTRAIN and its inspirational young GBM researchers

### PLUS:

Stories from our international brain tumour community:

United States  
United Kingdom  
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- Navigating your way through a brain tumour journey





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Walks can be done any time between

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The Walk Around the World for Brain Tumours in Ibadan, Nigeria (top photo) and Singapore (bottom photo)

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#### VARIATIONS IN SPELLING

Spelling in this publication varies according to country-specific practices and is thus variable throughout the magazine. For example, the word 'tumour' is spelled as 'tumor' in the United States but 'tumour' in the United Kingdom and Australia. Sometimes the term 'neuro oncology' is expressed without a hyphen and at other times with a hyphen as in 'neuro-oncology'. To preserve the international nature of this publication, the IBTA has varied the spelling accordingly.

## Dear Reader,

WELCOME to the 2019 edition of *Brain Tumour* magazine. This year, we are printing 14,000 hard copies and sending them for free to recipients in 111 countries as well as distributing them throughout the coming months at major international neuro-oncology and cancer conferences.

*Brain Tumour* magazine tells the inspirational stories of a determined community of people - young and old from all different backgrounds - whose lives have been touched by a brain tumour.

Over the past twelve months, I've had the great privilege of travelling to many parts of the globe, meeting members of our international brain tumour community face-to-face and listening to these stories being told by them, including in Japan, various countries in Europe, the United States and India. Languages and cultures may be very different but the devastating impact of a brain tumour diagnosis on the patient and family is similar across continents. Some stories in this edition of *Brain Tumour* magazine describe this impact while others focus on the efforts of dedicated patient advocates and healthcare professionals to overcome barriers to treatment access and quality care so that everyone, no matter where they live, can obtain the support they need.

As always, the IBTA is extremely grateful to everyone who has so generously shared their stories of courage, dedication and insight within these pages. Our heartfelt thanks to you all.



With best wishes,

**Kathy Oliver**

Chair, International Brain Tumour Alliance (IBTA)

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# Around the World with the IBTA

The IBTA has contacts in 111 countries around the world to whom it makes available its free annual magazine, *Brain Tumour*. There is no other magazine like *Brain Tumour* which reaches deep into the international brain tumour community and covers stories from patients, family members, healthcare specialists, researchers, scientists, professional societies and others. As well as being sent directly to contacts on the IBTA's unique database, copies of the magazine are also distributed at major national and international neuro-oncology and cancer conferences throughout the year.

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# Barriers to Accrual and Enrollment in Brain Tumor Trials

Eudocia Q. Lee

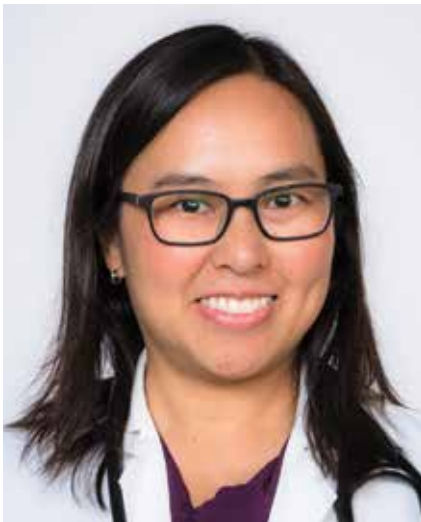
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Despite efforts to find better treatments for brain tumor patients, progress has been slow. While many factors contribute to this slow progress, one potentially modifiable factor is poor clinical trial accrual.

Before a drug or treatment regimen is approved for use in brain tumor patients by a country's regulatory agency (such as the Food and Drug Administration - FDA in the United States), the treatment must be studied in clinical trials. Clinical trials are designed to determine if a new treatment regimen can help patients. When accrual to a clinical trial is slow, it takes a longer time to determine if the treatment regimen is helpful or the trial may close early without answering the question. In general, when cancer patients are eligible and offered a clinical trial, more than 50% of patients enroll<sup>1-5</sup> (Figure 1).

However, the number of brain tumour patients enrolling in clinical trials is much lower. A 2016 survey of brain tumor patients and their caregivers by the National Brain Tumor Society (NBTS) revealed that only 21% of patients participated in a clinical trial.<sup>6</sup>

To this end, members from the Society for Neuro-Oncology (SNO) in collaboration with the Response Assessment in Neuro-Oncology (RANO) Working Group, patient advocacy groups including the International Brain Tumour Alliance, clinical trial cooperative groups, and other partners formed a coalition (Table 1) with the intent to double clinical trial accrual over the next five years. The first step was to describe the factors contributing to poor clinical trial accrual in neuro-oncology and offer possible solutions. The coalition summarized those findings categorized

according to patient and community factors, health care disparities, physician and provider factors, clinical trial factors, and site and organizational factors (Table 2). Here, we focus on factors most pertinent to patients and their caregivers.

## Patient-specific factors limiting trial participation

A wide range of patient factors could influence clinical trial participation. Some factors can affect any cancer patient, while other factors are unique to the brain tumor population given the tumor's impact on neurologic and cognitive function. Older age affects trial enrollment<sup>7</sup> as older patients tend to have more pre-existing medical issues and may not tolerate treatment as well as younger patients. Regardless of level of education, ➤



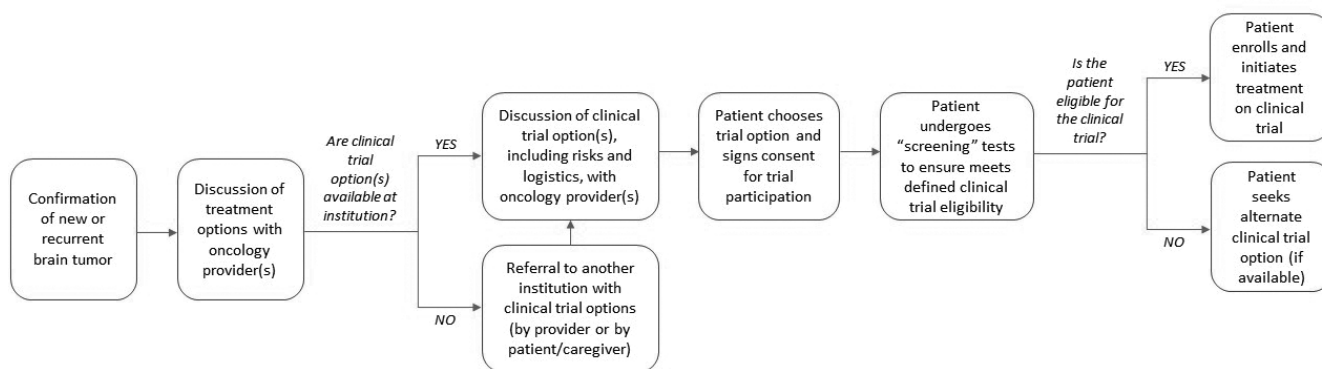


Figure 1: Understanding the process of clinical trial accrual and enrollment

patients and caregivers may have difficulty understanding the complexities of clinical trials.<sup>1,8-11</sup> How and when clinical trials are discussed with patients and caregivers can hinder enrollment, particularly during the emotional and psychosocial upheaval of a new or recurrent cancer diagnosis. Symptoms arising from the brain tumor itself may impact trial enrollment; patients with a greater degree of cognitive impairment are less likely to enroll onto clinical trials.<sup>12</sup> For underrepresented minority populations, clinical trial enrollment may be affected by disparities in the quality of health care arising from language barriers, limited access to health care, negative perception of clinical research, and the cultural competence of medical providers.

### Limited awareness of clinical trials

An important barrier to clinical trial enrollment is lack of awareness of clinical trials. In the 2016 NBTS survey of brain tumor patients and their caregivers, only 42% of patients were informed about clinical trials at any time during the course of their illness by their medical team.<sup>13</sup> Although many centers do not have trials to offer patients, the crucial importance of clinical research in improving care for brain tumors is a message worthy of discussion with all patients regardless of stage of treatment (thus also helping dispel the myth that clinical trials are only for those with advanced disease). A better understanding of the role of clinical research in advancing patient outcomes - in addition to the overall value of clinical research to society - also deserves greater public dissemination.

### Misconceptions about research study involvement

Another barrier to clinical trial participation is the misconception about risks and benefits of research study involvement. A patient may feel that a physician might offer a clinical trial for his or her own selfish reasons rather than to provide the best care for the patient. This may lead to a perception of lack of personal benefit for the patient and limit engagement in clinical trials. Importantly, the design of a clinical trial can dissuade some patients from enrolling; this barrier emphasizes the importance of early engagement with patients and advocates who can highlight some of these stumbling blocks. All efforts to enhance trial enrollment will be enabled by greater involvement of patients and advocacy groups via their input into the design of clinical trials at an early stage of a trial's development. One uncommon barrier (<10% of respondents) identified by the NBTS survey is the fear of experimental therapy toxicity, including life-threatening events.<sup>13</sup> Clear, honest communication of realistic risks and benefits of therapeutic interventions may reduce these barriers and enhance trial enrollment.

### Patient-related logistical constraints

Another prominent barrier to trial enrollment is the distance a patient is required to travel to participate.<sup>12,14-16</sup> Travel can be a barrier for many reasons, including a patient's inability to drive if they have seizures due to their brain tumor, financial burden linked to travel and lodging expenses, time away from work for patients and caregivers,

childcare costs, and overall stress related to travel. Opening trials at more centers, allowing delivery of standard of care radiation therapy closer to home, greater involvement of local oncologists, use of novel technologies such as telemedicine<sup>17,18</sup>, reducing the number of clinical trial visits, and resources to facilitate travel and lost income may help enhance trial participation. While patients are not paid for their participation on cancer clinical trials, the US FDA recently updated its guidance to clinical investigators allowing reimbursements to patients in clinical trials for lodging and travel.<sup>19,20</sup>

### Education campaigns and brain tumor registries may reduce barriers to trial participation

Treatment decisions for brain tumor patients are influenced by their treating physicians, caregivers, family, and friends. Although trial availability is an obvious requirement for trial participation, patients are motivated by access to the best possible treatments (which may give them a better chance of survival) and altruism.<sup>21</sup> Education campaigns should focus on reducing barriers to trial participation. Development of a brain tumor registry to quickly identify newly diagnosed cases with specific molecular profiles across the country could enable targeted education for these patients and physicians for early intervention, highlighting the potential benefits of precision medicine trials. Similar efforts are in place using the SPECTA platform by the European Organisation for Research and Treatment of Cancer (EORTC) for brain tumor patients (<http://www.eortc.org/specta/>; <https://>

clinicaltrials.gov/ct2/show/NCT02307604). Additional efforts to simplify identification of local studies (perhaps through development of an easily accessible website or smart phone App), clinical trial navigators, resources to facilitate travel, and engagement with advocacy groups and provision of patient navigators (Table 3) could all greatly improve trial enrollment.

## PLANS FOR THE FUTURE

The group's next step is to determine a roadmap to overcome and remove these barriers to clinical trial enrollment. Provider and patient educational campaigns as well as engagement with advocacy groups may help change the mindset of providers, patients, and caregivers to one where enrollment in clinical trials is the best option for most patients. This is now reflected in the National Comprehensive Cancer Network clinical practice guidelines for Central Nervous System Tumors where clinical trials are now the preferred option for most brain tumors.<sup>22</sup>

We must also harness modern technology to spread information about clinical trials through social media campaigns, a smart phone App that simplifies clinical trial searches for patients and caregivers, an increased number of patient navigators to guide patients through the process, as well as creation of national brain tumor registries where patients can contribute tumor tissues for sequencing which may help pair them with clinical trial options. Until we can expand clinical trial opportunities to more community-based settings (perhaps through a more efficient national clinical trial network, allowance of some components of the trials to be performed locally, and use of telemedicine for virtual visits), we advocate that any patient with a glioblastoma or uncommon brain cancer should be offered a referral to a major neuro-oncology center(s) in their relative proximity for consideration of clinical trials.

We must also critically evaluate clinical trial design to remove excessive burdens for participants. We will plan to work with the neuro-oncology community and clinical trial consortia to modernize eligibility criteria for brain tumor trials and to increase the number of high-quality clinical trials, especially in the National Cancer Institute National Clinical Trials Network in the US and the EORTC in Europe. ■

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**TABLE 1: Participants in the Clinical Trial Accrual Initiative**

(Please note: patients also contributed to this initiative but wished to remain anonymous)

NAME	TITLE AND ORGANIZATION
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<b>David Arons</b>	Chief Executive Officer, National Brain Tumor Society
<b>David Macdonald</b>	Neuro-Oncologist, University of Western Ontario (London, Ontario, Canada); RANO working group member
<b>David Sandak</b>	Senior Vice President, Strategy and Research, Accelerate Brain Cancer Cure (ABC2)
<b>Eudocia Q. Lee</b>	Neuro-Oncologist, Dana-Farber Cancer Institute (Boston, MA, USA)
<b>Evanthia Galanis</b>	Neuro-Oncologist, Mayo Clinic (Rochester, MN, USA); Chair, Neurooncology Committee, Alliance for Clinical Trials in Oncology
<b>John F. de Groot</b>	Neuro-Oncologist, MD Anderson Cancer Center (Houston, TX, USA)
<b>Joohee Sul</b>	Neuro-Oncologist, Medical Officer, US Food & Drug Administration
<b>Jose Pablo Leone</b>	Medical Oncologist, Dana-Farber Cancer Institute (Boston, MA, USA)
<b>Kathy Oliver</b>	Chair, International Brain Tumour Alliance (IBTA)
<b>Kay Verble</b>	Executive Director, The Sontag Foundation and The Brain Tumor Network
<b>Lisa Doherty</b>	Neuro-Oncology Nurse, Dana-Farber Cancer Institute (Boston, MA, USA)
<b>Marta Penas-Prado</b>	Neuro-Oncologist, National Cancer Institute, National Institutes of Health (Bethesda, MD, USA)
<b>Martin van den Bent</b>	Neuro-Oncologist, Erasmus University Hospital (Rotterdam, Netherlands); RANO working group member; Executive Board, European Association of Neuro-Oncology
<b>Maryam Fouladi</b>	Pediatric Neuro-Oncologist, Cincinnati Children's Hospital (Cincinnati, OH, USA); Chair, CNS Committee, Children's Oncology Group
<b>Michael Vogelbaum</b>	Neurosurgeon, Moffitt Cancer Center (Tampa, FL, USA); RANO working group member
<b>Michael Weller</b>	Neuro-Oncologist, University Hospital Zurich (Zurich, Switzerland); Chair, Brain Tumor Group, European Organisation for Research and Treatment of Cancer
<b>Minesh Mehta</b>	Radiation Oncologist with interest in brain tumors, Miami Cancer Institute (Miami, FL, USA); Chair, Brain Tumor Committee, NRG Oncology
<b>Nancy U Lin</b>	Medical Oncologist, Dana-Farber Cancer Institute (Boston, MA, USA); Chair, Brain Metastases Working Group, ASCO-Friends of Cancer Research Modernizing Eligibility Criteria Project
<b>Nicole Willmarth</b>	Chief Science Officer, American Brain Tumor Association
<b>Patrick Y. Wen</b>	Neuro-Oncologist, Dana-Farber Cancer Institute (Boston, MA, USA); President, SNO; RANO working group member; Co-Principal Investigator, Adult Brain Tumor Consortium
<b>Sarah Gaffey</b>	Research Project Manager in Neuro-Oncology, Dana-Farber Cancer Institute (Boston, MA, USA)
<b>Shawn L. Hervey-Jumper</b>	Neurosurgeon, University of California, San Francisco (San Francisco, CA, USA)
<b>Solmaz Sahebjam</b>	Neuro-Oncologist, Moffitt Cancer Center, Tampa, FL, USA
<b>Susan M. Chang</b>	Neuro-Oncologist, University of California, San Francisco (San Francisco, CA, USA); RANO working group member; Executive Board, SNO
<b>Terri S. Armstrong</b>	Neuro-Oncology Nurse with research interest in clinical outcomes assessment, National Cancer Institute, National Institutes of Health (Bethesda, MD, USA)
<b>Thomas Halkin</b>	Senior Manager of Communications, National Brain Tumor Society
<b>Ugonma N. Chukwueke</b>	Neuro-Oncologist, Dana-Farber Cancer Institute (Boston, MA, USA)

**Abbreviations:** ASCO: American Society of Clinical Oncology, RANO: Response Assessment in Neuro-Oncology, SNO: Society for Neuro-Oncology



TABLE 2: Factors impacting trial accrual and potential solutions

CHALLENGES	POTENTIAL SOLUTIONS
A: PATIENT AND COMMUNITY FACTORS	
Hindrances to patient's decision-making ability, including low level of education, limited understanding of clinical trials, and impact of disease on neurocognitive function	<ul style="list-style-type: none"> <li>■ Provider education to improve communication with patients regarding clinical trials (including written and online materials and videos)</li> <li>■ Engagement of patients and providers with advocacy groups</li> <li>■ Use of clinical trial patient navigator</li> </ul>
Patient's limited awareness of clinical trial opportunities	<ul style="list-style-type: none"> <li>■ Patient education campaigns focused on reducing barriers to trial participation</li> <li>■ Brain tumor registry to help providers identify trial eligible patients and to provide an opportunity for outreach to those patients</li> <li>■ Simplify the ability to identify local and national trials through improved online search tools, smart phone apps, or clinical trial patient navigators</li> <li>■ Engagement with patient advocacy groups and use of patient navigators</li> </ul>
Patient misconceptions about research study involvement including negative personal and family attitudes about clinical trials and perceived lack of personal benefit	<ul style="list-style-type: none"> <li>■ Patient education campaigns focused on demystifying clinical trials and dispelling rumors about them</li> <li>■ Engagement with patient advocacy groups which can promote the existence and benefits/risks of joining a clinical trial</li> </ul>
Suboptimal (i.e. poorly timed or rushed) discussion of clinical trial opportunities with overwhelmed patients/caregivers	<ul style="list-style-type: none"> <li>■ Heighten empathy for patients/caregivers</li> <li>■ Incorporate multimedia materials to effectively describe in layman's terms the study rationale, potential benefits/risks and logistics</li> <li>■ Improve informed consent documents and processes to facilitate greater understanding of the issues involved in clinical trial participation</li> <li>■ Provide sufficient time for patient/caregiver concerns to be addressed; incorporate additional research team input from nurses, mid-levels, and navigators</li> <li>■ Refer patients to brain tumor patient advocacy organizations for additional support and access to patient navigators</li> </ul>
Concerns about the complexity and difficulty of complying with protocols, cost, and time/convenience	<ul style="list-style-type: none"> <li>■ Design trials that are more patient friendly by obtaining their input</li> <li>■ Resources to facilitate travel and reduce costs of trial participation such as parking, housing, and absence from work</li> <li>■ Ensure coverage of routine patient care costs in clinical trials by both federal and private payers</li> <li>■ Open larger number of trials at smaller centers (a role especially for the National Clinical Trials Network in the United States)</li> <li>■ Use novel technologies such as telemedicine to minimize trips for clinical trial assessments</li> <li>■ Trial-design changes aimed at reducing the number of clinical trial visits</li> </ul>

## B: DISPARITIES

### Access and referral patterns

- Establish standard paradigm for referral of patients to neuro/medical oncology
- Implementation of patient navigators dedicated to support of URM/vulnerable patients
- Establish partnerships with community-based organizations serving URM

### Unconscious bias

### Lack of diversity in oncology workforce

- Unconscious bias training and regular evaluation of its efficacy and relevance
- Strengthen pipeline of URM candidates into neurology, oncology, neurosurgery and radiation oncology

## C: PHYSICIAN AND PROVIDER FACTORS

### Failure to discuss clinical trials as an option with patients

- Change standard practice to one where clinical trials are always discussed as an option in addition to existing standard therapies, particularly at two timepoints:
  - When formulating the initial plan of care
  - At the time of disease progression or disease recurrence
- Early on, dispel potential patient and caregiver attitudes that clinical trials are only for a time when all other options have run out, especially since patients who are heavily pre-treated are less likely to qualify for trials

### Time and inconvenience

- Trial navigators and/or electronic tools (e.g. apps) to allow for rapid, real-time trial matching
- Brief trial summaries pitched at physicians and at patients to provide a high-level overview of the trial rationale, design, risks/benefits, and visit schedule can distill complex information into some of the key elements
- Optimizing and streamlining referral processes on both the referring and receiving ends to reduce the barriers to referring patients to outside institutions for trials.

### Lack of knowledge

- For complex cases scheduled in advance, care team members could prepare ahead of the encounter to gather information on the best course of action
- If preparing ahead of the encounter is not possible, an alternative could be to acknowledge the complexity of the patient's case, and explain that further discussion with colleagues will take place (i.e., multidisciplinary tumor board) to identify the best course of action

### Lack of information about available clinical trials including eligibility criteria

- Take advantage of resources such as a clinical research navigator and on-line matching tools (e.g. apps), who can help identify clinical trials available at the institution that may be appropriate for each patient
- When a patient is a good candidate for clinical trials and there is not a trial available at the provider's institution, consider searching for studies available at referring center(s)
- Efforts to develop trial search engines which can provide

	<p>accurate and appropriate potential trial matches while minimizing manual data input from the provider, and which can filter for key factors (geography, stage, disease status, lines of therapy, relevant biomarkers) are underway and should continue</p>
<b>Lack of willingness to refer a patient to another center for study (including financial incentives)</b>	<ul style="list-style-type: none"> <li>■ Encourage a change in culture to always consider referring patients to centers with trials if one is not available locally, if practically feasible.</li> <li>■ Allow patients to receive some of their evaluations and treatments with the referring physician to reduce the sense that the physician is “losing” their patients; to validate the importance of a continued connection between the referring physician and the patient; to reduce the financial disincentive to refer patients; and to support stronger collaborations between oncology teams at the referring and trial sites</li> </ul>
<b>Lack of Incentive</b>	<ul style="list-style-type: none"> <li>■ Increase possibility of authorship for physicians who enroll patients into clinical trials</li> </ul>
<b>Concerns regarding a patient’s interest and ability to participate</b>	<ul style="list-style-type: none"> <li>■ A candid discussion with the patient and the research staff, ideally during the encounter to discuss treatment options, should be conducted to address any source of concerns for participation</li> </ul>
<b>Concern about the interference in the physician-patient relationship</b>	<ul style="list-style-type: none"> <li>■ Discussions about goals of care, patient’s preferences and expectations should be done during the clinical trial in the same manner as they are done during routine clinical care</li> </ul>
<b>Conflict between the physician’s role as caregiver versus scientist</b>	<ul style="list-style-type: none"> <li>■ There are at least three strategies to help mitigate this concern: <ul style="list-style-type: none"> <li>To place the patient’s needs and preferences first</li> <li>To enroll or refer to trials which are scientifically valid and designed in a clinically justifiable manner</li> <li>To explain the differences between the role of the primary oncologist and the role of the clinical investigator, particularly when they are embodied in the same person</li> </ul> </li> <li>■ Ask patients for any source of concerns about conflicts between the roles, and address them</li> </ul>
<b>Physician burnout</b>	<ul style="list-style-type: none"> <li>■ Understand and acknowledge the effect that clinical trials can have on physician burnout</li> <li>■ Work with institutional leadership to emphasize the value of access to clinical trials and the need for resources to facilitate clinical research.</li> <li>■ Work with the research staff, research nurses, clinical research coordinators and other personnel to address challenges to distribute the burden across the trial team.</li> <li>■ Future platforms, such as artificial intelligence may assist with curating clinical trial options.</li> <li>■ Shared electronic medical records across institutions may improve access.</li> </ul>



## D: CLINICAL TRIAL FACTORS

**Patient/caregiver hardships due to frequent study center visits limit enthusiasm for trial participation**

- Incorporate patient/caregiver/advocate feedback into early drafts of clinical trial during development
- Allow study assessments and treatments, especially those considered “standard of care” to be done locally;
- Require study center visits only when critically relevant to the study therapy;
- Proactively incorporate patient/caregiver considerations into need for regulatory requirements for source documentation

**Clinical trial design features lead to inefficient use of study participants**

- Incorporate multi-stage, multi-arm trials with adaptive randomization
- Incorporate careful toxicity and efficacy stopping rules
- Consider lower statistical power thresholds for non-registration efficacy trials
- Involve at an early stage of clinical trial design patient advocacy organizations, patients and caregivers

**Excessively stringent eligibility criteria limit trial participation**

- Limit inclusion/exclusion to criteria critically relevant to study primary endpoint
- Ensure eligibility criteria do not preferentially exclude a demographic or racial group, e.g. upper or lower age limits, or excluding comorbidities more highly associated with demographic or socioeconomic subgroup unless specific rationale for exclusion exists.
- Include patients with primary and metastatic brain tumors in early phase oncology clinical trials

**Technology trials ignore clinical equipoise challenges and incorporate traditional trial endpoints**

- Allow non-traditional primary endpoint/s that addresses key clinically meaningful objective of technology being assessed

## E: SITE AND ORGANIZATIONAL FACTORS

**Clinical research requires specialized personnel, training, infrastructure, resources**

- Effective leadership of a multidisciplinary team and organization culture to promote accrual
- Adequate infrastructure to allow clinical research
- Cancer care accreditation to incentivize trial enrollment
- Hire physicians and research staff committed to clinical research

**Slow activation of trials due to IRB issues, contracting issues, etc.**

- Centralize IRB operations with harmonization across countries

**Limited resources at community centers to support clinical research**

- Greater partnership between academic and community oncology centers
- Enhanced incentives for patient enrollment in clinical trials or referrals to academic centers for clinical trials
- Education programs for community physicians emphasizing the importance of clinical trials

**Abbreviations:** IRB - institutional review board URM - underrepresented minority

**TABLE 3: PATIENT ADVOCACY GROUPS**

NAME OF ORGANISATION	HEADQUARTERS	CONTACT INFORMATION	CLINICAL TRIAL RELATED SERVICES FOR PATIENT/CAREGIVERS
<b>Accelerate Brain Cancer Cure (ABC2)</b>	Washington, DC, USA	abc2.org 1-202-419-3140	Provides links to clinical trial resources through their website
<b>American Brain Tumor Association (ABTA)</b>	Chicago, IL, USA	www.abta.org 1-800-886-2282	Clinical trial finder and navigators available through TrialConnect app.emergingmed.com/abta/home or phone 1-877-769-4833
<b>Brain Tumor Network (BTN)</b>	Ponte Vedra Beach, FL, USA	www.braintumornetwork.org 1-844-286-6110	Professional staff conduct personalized clinical trial searches and provide treatment-related navigation throughout the continuum of care
<b>International Brain Tumour Alliance (IBTA)</b>	Tadworth, Surrey, UK	www.theibta.org +44 (0) 1737 813872	Links to international clinical trial portals available through their website
<b>Musella Foundation for Brain Tumor Research and Information</b>	Hewlett, NY, USA	virtualtrials.com 1-888-295-4740	Copayment assistance program; Clinical trial finder available through their website
<b>National Brain Tumor Society (NBTS)</b>	Newton, MA, USA	braintumor.org 1-617-924-9997	Clinical trial finder and navigators available through their website or phone 1-877-769-4812



## *Rare Cancers Europe (RCE)*

THE IBTA is actively involved in a wide range of high-level, international initiatives focussing on policy work to improve outcomes for rare cancers such as brain tumours. Working with a multi-stakeholder group of like-minded people, such as Rare Cancers Europe (RCE), pictured above, provides the IBTA with the opportunity to make a real difference in the lives of patients with rare cancers and their families. More than 4.3 million people in the European Union are affected by rare cancers. Despite the rarity of each of the 198 rare cancers, they represent in total about 22% of all cancer cases, including all cancers in children, diagnosed in the European Union countries each year. The IBTA is proud to serve on the RCE Steering Committee and to have been one of its founding members in 2008. ■

# I was a genomics cancer researcher when I was diagnosed with a glioblastoma fifteen years ago.

## Yaron Butterfield

North Vancouver, British Columbia, Canada

I was at a high point in my career at the Michael Smith Genome Sciences Centre (GSC) in Vancouver in April 2003 having played a key role in our successful effort to analyze and put together the SARS coronavirus genome. I had stayed up past 4:00 am on my own in the lab on a Friday night working with and analyzing the data with the hope of completing assembly of the genome sequence. When the full sequence appeared on my screen, I yelled in excitement but there was no one around to share my enthusiasm. The following day further analysis to confirm the result was needed and by the end of that day we aimed to publish the complete sequence before the Centers for Disease Control and Prevention (CDC) in Atlanta, Georgia. The news spread fast and put the GSC on the world-wide map. Life was good.

### My life changes forever

Ten months later, on February 23, 2004, my life changed forever. I collapsed in a grand mal seizure and was subsequently diagnosed with a very serious form of brain cancer – a grade 4 astrocytoma, also called glioblastoma multiforme (GBM). Now I'd have to deal with the fact that I had a cancer with an average survival of 13-15 months (if treated). However, being somewhat drugged up with medication, I do not think I fully grasped the seriousness of my situation. Perhaps I was in denial. As time went on, I started to feel that there was a reason I got the cancer. Indeed, I feel this last thought played a role in accepting my situation and in my survival.

Surgery to remove the tumour was a risky procedure given its deep location in my brain and so I went forward only with chemotherapy and radiation. I took a break from work to start treatment, and found time to start a new relationship,



Yaron Butterfield was diagnosed with a glioblastoma in 2004.

(Photo: Golnaz Sadjadi, [www.golnazsadjadi.com](http://www.golnazsadjadi.com))

go out and cheer my hockey team to a championship and ran a full marathon in Iceland, just a year-and-a-half after my diagnosis.

However, while planning to return to work, I had a recurrence in late 2005 and as the original chemotherapy rarely works a second time with GBM, I was placed on a clinical trial drug, which failed horribly. The bright side of things at the time was that I got married to the beautiful woman I had met the year before. But through the first eight months of 2006, I had to take the original chemotherapy drug as a last measure of hope that it would work. It did. I've been clear of brain cancer since September 2006.



Three-day hike in Jasper, Canada, 2016. For Yaron, hiking and being in nature is healing.





Yaron has participated in the Ride to Conquer Cancer (above left) along with his twin brother, Noam (above right), who has been with Yaron every step of the way since he was diagnosed with a brain tumour.



Yaron Butterfield

### Trying to get back to normal

I returned to work and continued researching various cancers including brain cancer (DIPG and oligodendroglioma). I wrote and published a piece of software to analyze RNA sequence data and during this time I worked hard in various capacities to contribute back to the brain cancer community. I helped initiate the first art therapy program at the British Columbia Cancer Agency (BCCA) for brain cancer patients.

I have personally enjoyed doing art ever since I was a kid. It has been an outlet to

get out thoughts that cannot otherwise be expressed either through text or speech. Sometimes, there are no words to convey what's in our complicated brains. My art often has intense and sometimes private meaning for me.

From another perspective, doing art has been extremely healing for me. Both in terms of being calm and in the moment, a type of meditation, and a way to surprise myself bringing thoughts from my unconscious to paper and canvas.

I also met with newly diagnosed patients, and co-chaired the Patient and

Family Advisory Committee for brain cancer patients at the BCCA.

For seven years I coordinated Brain Tumour Foundation of Canada's Spring Sprint, a walk/run where I met and was inspired by other brain cancer patients. I did the first Ride to Conquer Cancer after creating a team called the Brainiacs in 2009 with another GBM survivor. This was a two-day 280-ish kilometre bike ride, fundraising for cancer research. More recently I've been involved in a couple of initiatives here in British Columbia centered on patient involvement in healthcare - a very important and exciting initiative that hopefully will overhaul the health system for the benefit of all: patients, caregivers, healthcare teams and researchers.

It's been an amazing journey since my life changed forever instantly on that day in 2004.

### My inspirations

I now have a beautiful daughter which adds to my inspiration to thrive and get the most out of life. Many people over the years have asked me how and what did I do to survive, many hoping to hear about specific things that they could apply to their own situations such as specific diets, foods, drugs, and supplements. My response has always been that we are all different and what works for one may not work for another.

Ultimately, we need to leverage our mind (which can be hard when the cancer is in the brain!) and soul to heal ourselves. ➤



Yaron (centre), Rosie Cashman, Nurse Practitioner at the BC Cancer Vancouver Centre (right) and Dr. Brian Thiessen, neuro-oncologist at BC Cancer Vancouver Centre (left). (Photo credit: Reid Lucier)



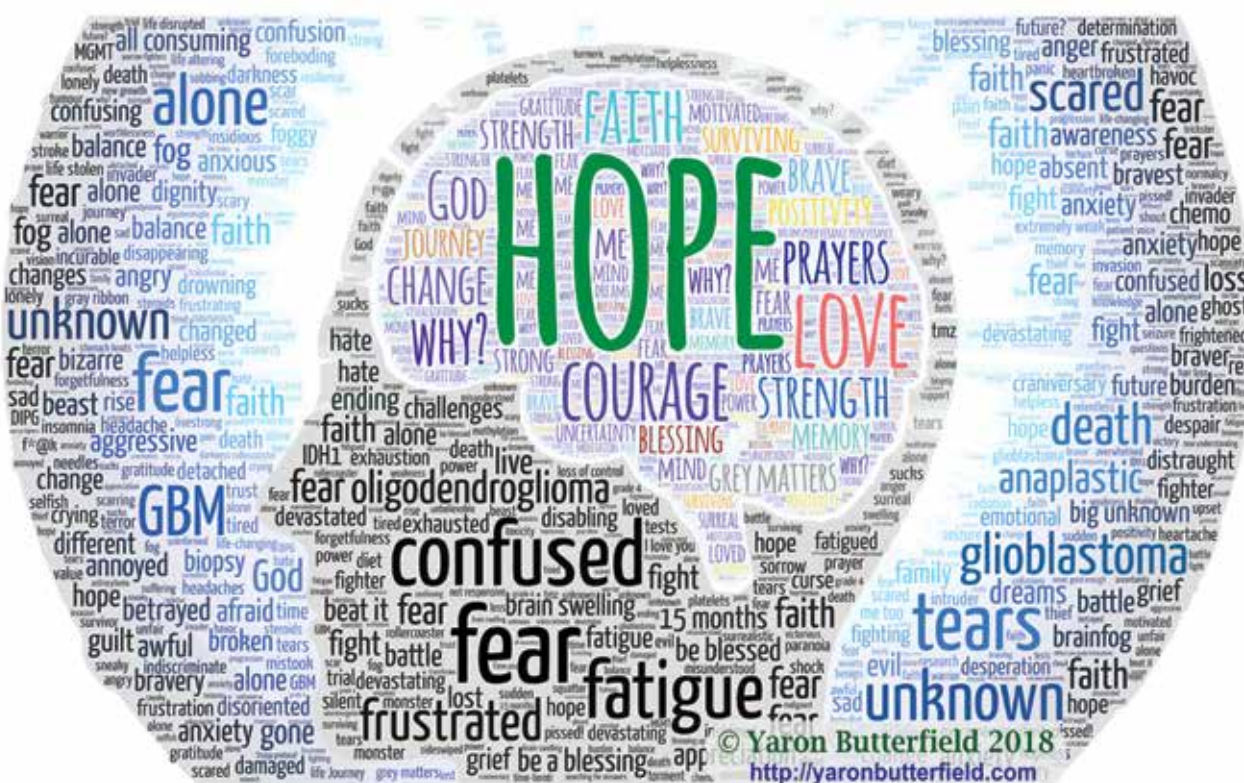
We have tremendous power and strength to do just that. Not that medical treatments do not work; I would not be here to write this had I not taken chemotherapy and radiation. But there is increasingly strong evidence that positive thoughts can have a biological and biochemical effect on our bodies.

For those interested in some specifics, my tumour had the IDH1 R132H mutation and MGMT promoter methylation; consistent with my age (29) of presentation and favourable prognosis. ■

The above article has been abridged from Yaron Butterfield's website and reproduced in *Brain Tumour* magazine with his kind permission. For more information on Yaron, and to get updates on his upcoming memoir, please visit <http://yaronbutterfield.com>



Yaron also exhibits his artwork at the annual BCCA Art Show in Vancouver, Canada. He says: "Art has been an outlet to get out thoughts that can't otherwise be expressed either through text or speech." (Photo credit: Reid Lucier)



THIS is a word cloud that Yaron Butterfield created. Word clouds (sometimes also called text clouds or tag clouds) are a simple concept: the more frequently a specific word appears in a data source (ie a survey, speech, presentation, seminar, database, etc) the bigger and bolder it appears in the word cloud. In other words, word clouds are images made up of words used in a specific context, where the size and boldness of the word indicates its importance or frequency.

For his word cloud, Yaron canvassed seven brain cancer/tumour Facebook groups and asked people to give him words that described their journeys following diagnosis. Yaron received over 300 words from around the world and created this word cloud image using all the words he was sent.

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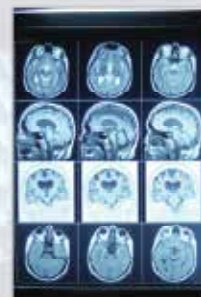
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- Extensive video library
- Brain Tumor Virtual Trial
- Toll Free Patient Help Line: 1-888-295-4740

### Brain Tumor Research

- Funded over 40 brain tumor research projects
- Fundraising for brain tumor research

### Brain Tumor Activism

- Organizes the brain tumor community to fight for FDA approval of drugs and devices, as well as insurance company payment for these treatments.

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# NCI-CONNECT Develops Infrastructure to Understand Rare CNS Tumors

Mark Gilbert, M.D., Chief

Terri Armstrong Ph.D., Deputy Chief

Neuro-Oncology Branch, Center for Cancer Research, National Cancer Institute (NCI), National Institutes of Health (NIH), United States; Co-directors, NCI-CONNECT (Comprehensive Oncology Network Evaluating Rare CNS Tumors)

*In October 2017, Drs. Mark Gilbert and Terri Armstrong launched NCI-CONNECT to establish paradigms to study 12 rare adult central nervous system (CNS) cancers, each with less than 2,000 people diagnosed a year in the United States (see adjacent infographic for tumor list). NCI-CONNECT is a project supported by the Cancer Moonshot<sup>SM</sup>, a key initiative at NCI. The Moonshot seeks to accelerate cancer research to make more therapies available to more patients, while also improving the ability to prevent cancer and detect it at an early stage. Its ambitious goal is to make a decade's worth of progress in cancer prevention, diagnosis, and treatment in just five years.*

We recognize that under the Cancer Moonshot<sup>SM</sup> we have an unprecedented opportunity. Our aim is to advance the understanding of rare adult CNS cancers by establishing and fostering patient-advocacy-provider partnerships and networks to improve approaches to care and treatment.

Our program goals are detailed in the adjacent infographic. In 2018, we made important accomplishments towards them. We are excited to share our progress and plans.

## Networks and Partnerships

We partnered with the Central Brain Tumor Registry of the United States (CBTRUS) to determine the incidence and prevalence of our select 12 rare adult CNS cancers. The data are critical to further understand these tumors and educating patients and providers.

We established a national network of centers willing and eager to participate in studying rare CNS tumors to find better therapies and improve patient outcomes. The network will participate in NCI-CONNECT clinical studies and develop multi-center clinical trials. We hope to launch our first multi-center trial in 2019. We are also collaborating with national cooperative groups such as NRG Oncology and Alliance Oncology as well as international groups such as the Peter Mac Cancer Center in Australia.

NCI-CONNECT has also partnered with non-profit organizations which share a common concern for improving the outcomes of patients with rare adult CNS tumors through awareness



Dr. Mark Gilbert, Chief, Neuro-Oncology Branch at NCI

and education. We have developed formal relationships with the American Brain Tumor Association (ABTA), Collaborative Ependymoma Research Network (CERN) Foundation, EndBrainCancer Initiative, International Brain Tumour Alliance (IBTA), National Brain Tumor Society (NBTS), and Oligo Nation.

To enhance education and outreach, we built a website at [cancer.gov/nci-connect](http://cancer.gov/nci-connect). It includes tumor type information, ways to cope and guiding questions at every stage of the cancer journey, clinical study information, and a blog called NCI-CONNECTIONs to share news and information on advances in research, treatment, and education from our experts.



Dr. Terri Armstrong, Deputy Chief, Neuro-Oncology Branch at NCI

## Clinical Studies and Trials

Our networks and partnerships are key to helping us enroll patients on clinical studies and trials, which is a significant challenge for rare tumor research. Our current clinical studies include an online Outcomes and Risk Project that patients can participate in from their home. It is an online survey that also includes collection of a saliva sample for genetic testing. Our Natural History Study aims to better understand CNS tumors and uncover areas for further research. It also aims to connect patients with doctors who can help them manage their illness and give them new treatment options. To participate, ➤

## Comprehensive Oncology Network Evaluating Rare CNS Cancers (NCI-CONNECT)

### Advancing the Understanding of Rare Adult Brain & Spine Cancers



Connecting patients, providers, researchers, and community organizations to work in partnership



Investigating new therapies to improve patient outcomes



Collecting, analyzing, and sharing data to enable a better understanding and develop standard of care

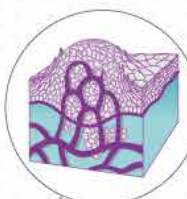
Improving approaches to care and treatment for people living with a brain or spine tumor

### Studying Rare Brain and Spine Tumors



#### FEWER PATIENTS MEAN...

....it's harder to test possible therapies



....and it's harder to get tumor tissue to help researchers study and learn about cancer



#### NCI-CONNECT IS ADDRESSING THESE CHALLENGES STARTING WITH THE FOLLOWING TUMORS:

- ATRT
- Choroid Plexus Tumors
- Diffuse Midline Gliomas
- Ependymoma
- Gliomatosis Cerebri
- Gliosarcoma
- Medulloblastoma
- Meningioma (High Grade)
- Oligodendroglioma
- Pineal Region Tumors
- PXA / APXA
- PNET

EACH WITH LESS THAN 2,000 PEOPLE DIAGNOSED PER YEAR





Neuro-oncology researchers, physicians, and advocates gather at the NCI-CONNECT Oligodendroglioma Workshop, held at NIH in November 2018. The scientific workshop brought together multidisciplinary experts to discuss fundamental, translational, and clinical research. (Photo reproduced with kind permission of NCI)



Drs. Terri Armstrong (seated center), Marta Penas-Prado (right), and Mark Gilbert (far right), of NCI-CONNECT, care for a person in clinic. NCI-CONNECT physicians see patients in the NIH Clinical Center in Bethesda, Maryland, United States. (Photo reproduced with kind permission of NCI)

patients visit NIH for a consultation and provide tumor tissue for pathology review.

Currently enrolling clinical trials in NCI-CONNECT include a Rare Adult CNS Cancer Immunotherapy Trial and CNS Sarcoma/Gliosarcoma Trial with more studies planned.

### Specialty Clinics and Workshops

In January 2019, we launched disease-specific specialty clinics at NIH in Bethesda, Maryland, United States. Our NCI-CONNECT Clinics occur weekly and bring together adult patients with the same rare CNS tumor and their caregivers to receive special services. These services include genetic counseling and testing, molecular tumor testing, outcome reporting, health and wellness support, and clinical trial information. We encourage national and international providers to refer patients to NIH that generates a partnership with providers on the care and treatment of their patients.

NCI-CONNECT has also launched a series of disease-specific workshops. Participants are experts across research and clinical specialties. NCI-CONNECT has hosted



The NCI's Neuro-oncology Branch team gathers to review and discuss the best treatments for their NCI-CONNECT patients. Led by Dr. Mark Gilbert, the tumor board includes multidisciplinary experts. Photo reproduced with kind permission of NCI.

workshops on histone-mutated gliomas, oligodendrogliomas, ependymomas and next, medulloblastoma. We are also partnering with the IBTA to host their 2019 World Summit of Brain Tumour Patient Advocates at NIH.

### Participating in NCI-CONNECT

Our partnerships and collaborations with

providers, patients, and advocates allow us to share knowledge, thereby improving care for patients and patients yet to be diagnosed with these rare CNS tumors.

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■ **Providers:** NCI-CONNECT wants to work with you to identify patients eligible for clinical trials and studies.

■ **Advocates:** NCI-CONNECT wants to partner with your organization to share resources and educational information.

We believe the NCI-CONNECT model of building partnerships and networks could have a huge impact. And, hopefully, if successful, we can apply our approach to all CNS cancers and rare cancers in general. ■

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- Ependymoma
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- Gliosarcoma
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- Meningioma (High Grade)
- Oligodendroglioma
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# The Society for Neuro-Oncology Sub-Saharan Africa (SNOSSA) - an update on progress

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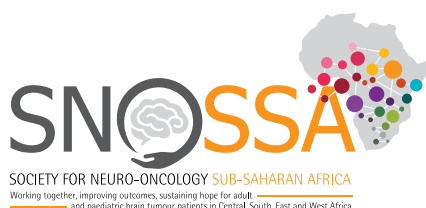
James Balogun



Jeannette Parkes



Alan Davidson



The Sub-Saharan Africa Neuro-Oncology Collaborative (S-SANOC) planning meeting which took place at the Tower Hotel, London, United Kingdom in October 2017 formed the foundation for the birth of the Society for Neuro-Oncology Sub-Saharan Africa (SNOSSA). The meeting was organized through the collaborative efforts of the Society for Neuro-Oncology (SNO), the International Brain Tumour Alliance (IBTA), and the Zimbabwe Brain Tumour Association (ZBTA), in association with Mark Bernstein, the Greg Wilkins-Barrick Chair of International

Surgery at the University Health Network, University of Toronto, Canada. There were 33 participants from 16 countries with good representation across Sub-Saharan Africa.

The meeting was primarily set up to give groups that had applied for the right to host a state-of-the-art symposium or educational course in Sub-Saharan Africa in 2018 the opportunity to present their proposals. However, with the presence of representatives from almost all clinical sub-specialties that deal with brain tumours together with brain tumour patient advocates from Sub-Saharan Africa, the meeting provided the needed environment for a multi-stakeholder engagement to facilitate a Sub-Saharan African neuro-oncology society that hopes to take a leadership role in coordinating efforts to improve patient care in the region.

The meeting resulted in a general consensus by the participants about the necessity for a neuro-oncology society whose membership will include patient advocates. A steering committee was put in place to facilitate a course to be hosted at the first annual meeting of the Society for Neuro-Oncology Sub-Saharan Africa (SNOSSA) in Abuja, Nigeria.

## SNOSSA's first conference

The first conference of SNOSSA was held at the Transcorp Hilton Hotel, Abuja on 22 and 23 July 2018. The meeting was attended by delegates from Sub-Saharan African countries as well as speakers drawn from the United States, United Kingdom, Canada, India and Greece. The meeting provided an opportunity to explore the neuro-oncology landscape in the region, with insight into CNS tumour



epidemiology, as well as the challenges faced by those who practice across sub-specialties and countries. Speakers also shared perspectives about practices in other low and middle income countries such as India, as well as from high-income countries.

A session on patient advocacy brought the issues of collaboration between physicians and patient advocates to the fore. These include the need for increased listening and empathy by providers, and the need to document the available neuro-oncology capacity in Sub-Saharan Africa to facilitate access to services. The meeting also gave the participants the opportunity to discuss education, research and collaboration within and outside Africa. The meeting culminated in the adoption of a constitution for SNOSSA, the election of a substantive executive council, setting up of a board of trustees and the awarding of the hosting rights for the 2019 SNOSSA meeting to Cape Town, South Africa.

### **SNOSSA's collaborative efforts**

SNOSSA continues to partner with sister organizations such as the Society for Neuro-Oncology (SNO), European Association of Neuro-Oncology (EANO) and the Society for Neuro-Oncology Latin America (SNOLA) as well as the International Brain Tumour Alliance (IBTA).

Discussions for definite collaboration are ongoing with the American Society of Clinical Oncology (ASCO). SNOSSA is also looking to partner with the African Organization for Research and Training in Cancer (AORTIC) to facilitate a session for CNS tumours at the organization's

12th annual conference in Maputo, Mozambique in November 2019. We are also working with SNO to develop and launch a web-based database of neuro-oncology professionals in Sub-Saharan Africa. We are seeking to build and maintain relationships with allied health care providers, patient advocates/patient advocacy organizations and members of the African diaspora in the field of neuro-oncology who do some work on or visit the continent. We are hopeful that these collaborations will make the engagements of SNOSSA towards advocating and providing greater care for neuro-oncology patients more robust, in addition to the membership drive across the continent.

### **The second annual meeting of SNOSSA in Cape Town, South Africa**

The second annual meeting of the Society for Neuro-Oncology Sub-Saharan Africa (<http://www.snossa.org/>) will be hosted in conjunction with the South African Paediatric Brain Tumour Workshop (PBTW) at the

University of Cape Town (UCT) on 7th and 8th August 2019.

The meeting will be held at UCT's Faculty of Health Science at the Wolfson Pavilion. It will run concurrently with pre-conference workshops of the South African Congress of Oncology (<https://www.saco2019.co.za>). In addition, the Society of Neurosurgeons of South Africa (SNSA- <https://www.snsa.co.za>) will host a meeting with the Society of British Neurological Surgeons (SBNS) in Cape Town over the same weekend. The philosophy of the SNOSSA conference is to present multi-disciplinary issues in pediatric and adult neuro-oncology in a thematic and integrated fashion.

We will have a world class faculty from across the globe. Keynote lectures will be given by neurosurgeon Dr Frederick Lang on awake surgery and intra-operative mapping. Dr Rakesh Jalali will discuss implementing state of the art neuro-oncology in the low-and-middle-income-countries (LMIC) setting. Dr Patrick Wen will deliver the ➤



The first SNOSSA conference in Abuja, Nigeria was a great springboard for neuro-oncology activity in Sub-Saharan Africa. Here are just a few photographs of the event in July 2018 which saw healthcare professionals and patient advocates working together to improve outcomes for people with brain tumours and their families in Africa.



first SNO Lecture on neurologic complications of cancer and its treatment. Kathy Oliver of the International Brain Tumour Alliance (IBTA) will address the networking event.

Other highlights include Dr Normand Laperrière presenting on radiotherapy for germ cell tumours; Dr Ricardo Soffietti of EANO on managing metastases; Dr Evangelia Razis on small molecules and TKIs; and neurosurgeon Dr Gelareh Zadeh on managing meningioma. Neurosurgeon Dr Shawn Hervey-Jumper will consider the case for surgery in low grade gliomas (LGGs), Dr Jason Huse will present on the implications of WHO 2016 for the neuropathologist; Dr Mark Gilbert will discuss the modern management of ependymoma and glioblastoma (GBM) and neurosurgeon Dr Edjah Nduom will address the potential for checkpoint blockade in GBM.

Local talent includes Dr Tracy Kilborn (Medulloblastoma - can MRI predict molecular subtypes?); Dr Allan Taylor (Managing AVMs - a multi-disciplinary approach); Dr Graeme Wilson (Anaesthesia for paediatric imaging and radiotherapy) and neurosurgeon Dr Anthony Figaji (Using neurophysiology in brainstem and spinal cord surgery).

There will be an "Ask the Expert" session with a panel of experts commenting on proffered vignettes and the meeting culminates in a number of breakaway sessions: a radiotherapy contouring workshop by Dr Normand Laperrière, a neurosurgical workshop, a medical and paediatric MDT and an advocacy workshop.

We are expecting adult and pediatric health professionals who treat CNS tumours, allied health professionals, advocacy groups and health care managers to attend the SNOSSA 2019 meeting in Cape Town. Additionally, trainees in neurosurgery, radiation and medical oncology, pediatric oncology, and palliative medicine are invited, and they are eligible for Society for Neuro-Oncology sponsored travel awards. Applicants will need to submit an abstract in the form of a clinical vignette which may be put to our experts or used in the oncology MDT. ■

**For further details on the SNOSSA 2019 conference in Cape Town, South Africa, please visit <http://btw.brainchild.org.za/>**

**SNO** Society for Neuro-Oncology

**IBTA** INTERNATIONAL BRAIN TUMOUR ALLIANCE

**ZBTMA** ZIMBABWE BRAIN TUMOUR ASSOCIATION

## Report of the first Sub-Saharan Africa Neuro-Oncology Collaborative (S-SANOC) Planning Meeting

working together...improving outcomes...sustaining hope  
for adult and pediatric brain tumour patients in  
central, south, east and west Africa

**18th - 20th October 2017**  
The Tower Hotel, London, United Kingdom

GREATER COLLABORATION ■ GREATER KNOWLEDGE ■ GREATER HOPE

The Society for Neuro-Oncology Sub-Saharan Africa (SNOSSA) arose after a meeting in London in October 2017 which brought together a range of stakeholders focusing on the care and support of people with brain tumours living south of the Sahara on the African continent.

Thirty-three participants from 16 countries attended the 2017 Sub-Saharan Africa Neuro-Oncology Collaborative (S-SANOC) meeting in London. The meeting was run by the International Brain Tumour Alliance (IBTA) in conjunction with the Society for Neuro-Oncology (SNO); the Zimbabwe Brain Tumour Association (ZBTA); Dr Mark Bernstein (the Greg Wilkins-Barrick Chair in International Surgery, University of Toronto, Canada); and the SNO Wilkins-Barrick Course in Neuro-Oncology.

Once SNOSSA had formed after the 2017 London meeting, the first SNOSSA conference in Abuja, Nigeria was an event that brought great minds together to ponder on the achievements made so far and the way forward for brain tumour care. Improving the quality of care while advocating for people suffering from brain tumours was a keynote of this meeting.

SNOSSA's mission is: "Working together, improving outcomes and sustaining hope for adult and pediatric brain tumour patients in central, south, east and west Africa".

To read the online report of the S-SANOC meeting in London please go to [https://issuu.com/ibta-org/docs/ibta\\_ssanoc-report\\_final\\_20mar2018](https://issuu.com/ibta-org/docs/ibta_ssanoc-report_final_20mar2018)



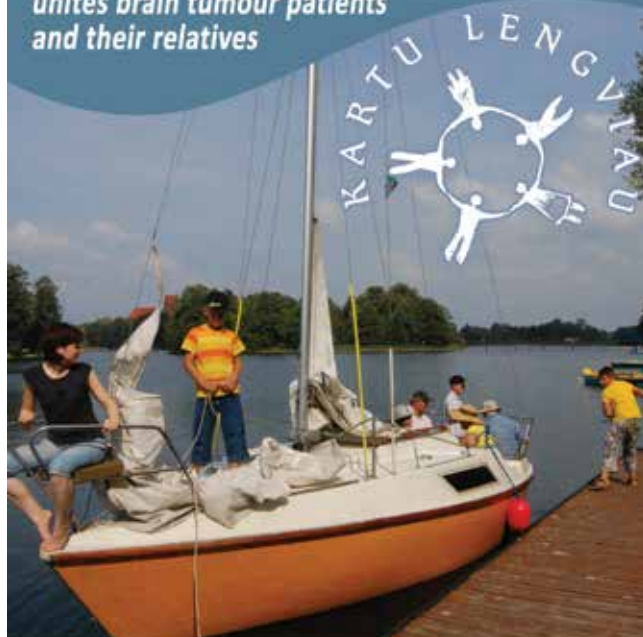
### The ZBTA Continues to :

- Advocate for improvement in the access to treatment, early diagnosis and provision of quality care for brain tumour patients and survivors in Zimbabwe.
- Co-ordinate the efforts of all stake-holders in reviewing, as well as setting policy frame works and standards in provision of better services.
- To provide hope and deliver better treatment outcomes for patients such as : -
  - Well equipped theatres
  - Advanced brain tumour treatment machinery
  - Brain tumour research centres
  - Access to affordable diagnostic imaging services
- Running campaigns to have all health personnel in satellite clinics sensitized on signs and symptoms of brain tumours

**Achieving Through Hope & Strength**

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 and their relatives



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# ISNOCON 2019 - a forum for multi-disciplinary collaboration

The 11th Annual Conference of the Indian Society of Neuro-Oncology in Bhopal, India from 5th to 7th April 2019

## Dr Nitin Garg

Neurosurgeon, Bansal Hospital, Chuna Bhatti, Bhopal, Madhya Pradesh,  
India and Organising Secretary, ISNOCON 2019

## Namaskar\*

Brain tumors represent less than 1-2% of all the newly diagnosed cancers in India. Though this represents a small figure, it is a catastrophic illness which brings with it a sense of insecurity and despair for the patient and the family. In a survey of brain tumor-affected patients, the two most important things that patients want post treatment are to retain the brain function and to maintain their ability to walk and perform basic physical tasks of daily living independently. The fear of disability following surgery and radiotherapy is one of the main reasons of delayed treatment resulting in poor outcomes.

The 11th Annual Conference of the Indian Society of Neuro-Oncology (ISNOCON) was held in Bhopal, India from 4th to 7th April 2019 at Hotel Jehan Numa Palace, a heritage venue. This was the first time it was held in a "Tier-2" city (Indian cities are classified into tiers in terms of real estate, business and commercialisation) in a non-institutional set up. The meeting saw the highest attendance in the history of ISNOCON since its inception.

Three hundred and fifty delegates from various specialities such as neurosurgery, radiation, medical and pediatric oncology, neuropathology, neuroradiology, psychology and molecular biologists/scientists participated with 13 international faculty from Canada, United States, United Kingdom, Germany and South Korea. National faculty from all of the major Indian institutions like AIIMS, New Delhi; Tata Memorial Hospital, Mumbai; PGI,



Dr Nitin Garg, Organising Secretary, ISNOCON 2019

Chandigarh; SGPGI, Lucknow; NIMHANS, Bangalore; CMC, Vellore; KEM, Mumbai and private hospitals such as Medanta Hospital (Gurgaon), Fortis, Artemis Hospital

(Gurgaon), Yashoda Hospital, Bombay Hospital and Apollo Proton Centre (Chennai) participated in this event.

Three workshops in neurosurgery, radiation oncology and molecular neuro-oncology were held as part of a pre-conference activity on 4th April.

In the neurosurgical workshop, techniques to demonstrate resection of eloquent cortex gliomas using intra-operative neuro-monitoring (IONM) were held with two live surgeries.

In the radiotherapy contouring workshop, students were trained on treatment planning stations (TPS) about effective contouring in various tumors, such as gliomas, metastases, pituitary adenomas and meningiomas.

Lastly, the molecular neuro-oncology workshop gave hands-on training to participants for immuno-flourescent cytochemical detection of tumor markers by



For the first time at ISNOCON there was a whole session on psycho-oncology which was attended by brain tumor patients and their families



IBTA Chair and Co-Director Kathy Oliver delivering a keynote lecture on 'The Impact of Patient Advocacy Groups on Global Neuro-Oncology' at ISNOCON 2019

liquid cytology (IF-ICC), dot immuno-binding assay (DIA) for detection of proteomic markers from blood and flow cytometry for detection of brain tumor stem cells.

All three workshops were well attended.

The theme of this year's conference was sellar and suprasellar tumors with special emphasis on pituitary adenomas and craniopharyngiomas. Various surgical and radiotherapy techniques and long term results in these tumors were discussed. Importantly, dedicated talks by eminent endocrinologists Dr Nalini Shah and Dr Anurag Lila emphasised the long term endocrinological outcomes and methods to treat and correct these.

An entire session at ISNOCON was devoted to intracranial germ cell tumors. A framework for consensus guidelines for management of these tumors was formulated. These will be published in due course.

Professor Eric Bouffet (The Hospital for Sick Children, Toronto, Canada) delivered the Ab Guha Oration in memory of Prof Abhijit Guha, a greatly admired and respected neurosurgeon who was born in Kolkata but who lived in Canada and practised neurosurgery at the University of Toronto. Dr Guha passed away in 2011, age 54, from acute myeloblastic leukemia. In his oration, Prof Bouffet emphasised the limitations in providing optimal and timely treatment for pediatric brain tumor patients in developing countries.

ISNO President, Dr Suresh Sankhla, in his presidential address highlighted the advances of endoscopic surgery for sellar and suprasellar tumors.

A keynote lecture was delivered by Prof Yong-Kil Hong, President of WFNOS, on oncolytic virus therapy in gliomas. This seems an exciting option with promising results in the preliminary clinical trials.

Dr Vinay Puduvalli and Dr Ching Lau from the United States, Dr Marcel Kool from Germany, Dr Seok-Gu Kang from South Korea and Ms Kathy Oliver from the International Brain Tumour Alliance (IBTA) delivered the other keynote lectures. Ms Kathy Oliver highlighted the importance of brain tumor support groups in providing better aftercare, raising funds for research and spreading awareness about the challenges of brain tumors.

Neuro-oncologists have traditionally focussed on improving therapeutic strategies for brain tumor patients. However, psycho-social needs of the patients and their caregivers must also be addressed in a more structured manner. Hence, the 11th ISNOCON had an entire psycho-oncology session dedicated to this purpose. Patient support groups, such as the Brain Tumor Foundation of India (BTF) and the International Brain Tumour Alliance (IBTA) actively participated in this session to deliberate and guide on this important but neglected issue.

Dr Soumitra Dutta, pediatric psychiatrist from the Tata Medical Centre, Kolkata,



Dr Savita Goswami, a psycho-oncologist from the Tata Memorial Hospital in Mumbai moderated the session with brain tumour patients, caregivers and families at ISNOCON 2019.

presented a road map on how to set up pediatric psycho-oncology services in routine clinical practice. Dr Prakash Chitalkar, a medical oncologist and advocate of support groups discussed the issues faced by teenagers and young adults (TYA) with various malignancies including brain tumors.

Dr Savita Goswami, a psycho-oncologist from Tata Memorial Hospital in Mumbai, conducted two panel discussions - one involving patients and their caregivers and the other involving psychiatrists, psychologists, patient support group advocates and clinicians. About 20 patients, some of whom are still undergoing treatment for their brain tumors, were present with their families in these interactive sessions. Some of them were highly-qualified professionals, such as an architect, interior designer, banker, managerial executive and a practising doctor. Important issues highlighted in this session were as follows:

1. The importance of a multi-disciplinary team for appropriate and prompt diagnosis and post-operative management. Some tumors may have unusual presentations, such as hormonal imbalances, visual impairment or metabolic syndromes. A multi-disciplinary team helps in arriving at a prompt diagnosis. ➤





Dr R K Panday (left), Organising Chairman of ISNOCON 2019 and Dr Tejpal Gupta, General Secretary of ISNO



Radiation Oncologist Dr Rakesh Jalali, ISNO Advisory Council member

2. Effective communication. This was stressed unanimously. There is a fear of the unknown in the minds of brain tumor patients and their caregivers.

Effective communication regarding the disease, treatment related aspects, long term survivorship issues and quality of life allays anxiety and prepares them better to undertake treatment. The Brain Tumor Foundation of India has been working relentlessly in achieving this goal of easier communication and publishes brain tumor booklets in nine Indian languages including English. These booklets give information on various aspects of brain tumors such as diagnosis, treatment, follow-up, prognosis, various clinical trials and links to websites on brain tumors.

3. Apprehension regarding tumor recurrence. Anyone who has successfully completed treatment fears a recurrence. Tumor support groups can help to allay these fears to an extent.

4. Social Integration. There is limited access to information about brain tumors in society. Anyone who has successfully conquered the treatment path may still find it difficult to get back to their routine profession. "Will he/she be competent enough?"; "Are they more prone to errors?"; "Will they be able to expend the effort?". These are just some of the questions in the minds of employers and colleagues. Some of the brain tumor

patients at ISNOCON 2019 shared that work-place support in terms of job security, financial assistance, and understanding colleagues are very important in reducing their stress levels. Support groups need to work on better sensitisation and awareness amongst the policy makers and society to address these aspects more humanely and without ambiguity.

5. Narrative medicine. "Providing a platform to express patients' and caregivers' pent-up feelings has a positive impact and significantly reduces their psychological burden," stated Ms Kathy Oliver, co-founder and director of the IBTA. While listening to the patients and caregivers at ISNOCON, she highlighted that in her experience with her own son who had a brain tumor, most patients and caregivers wanted to share their difficult journey with others. She outlined the concept of "narrative medicine" which is an interdisciplinary field that encourages listening and creativity to improve healthcare. Through narrative medicine, patients and caregivers can voice their fears, triumphs and hopes so these experiences can be recognised and valued, thus humanising healthcare delivery.

The session also marked the inauguration of the "Brain Tumor Support Group of Bhopal". This group will conduct

bi-monthly meetings of brain tumor-affected patients and their family members. Dr Rakesh Jalali, an expert in the field of neuro-oncology, has held such sessions at the Tata Memorial Hospital in Mumbai, from 2002. He said that such self-help groups motivate patients and their relatives and instill confidence in them to overcome this difficult phase in their lives.

The famous Indian physician Charaka, the "Father of Indian Medicine of Ayurveda", mentioned in the second century BC: "A physician who fails to enter the body of the patient with the lamp of knowledge and understanding can never treat diseases. He should first study all the factors, including environment, which influence a patient's disease, and then prescribe treatment."

ISNO - with its multi-disciplinary approach and collaborative spirit - follows the same principle.

As a tribute to all those who have guided and led ISNO, a brief video on the History of ISNO was released at ISNOCON 2019 in Bhopal which is accessible online here: <https://youtu.be/jZ122uKGtfo>. ■

**Dr RK Panday, Consultant Radiation Oncologist and Dr Nitin Garg, Consultant Neurosurgeon at Bansal Hospital, Bhopal organised ISNOCON 2019 in association with Bhopal Neuro-Association and Bhopal Oncology Society.**

## An ISNOCON 2019 Album



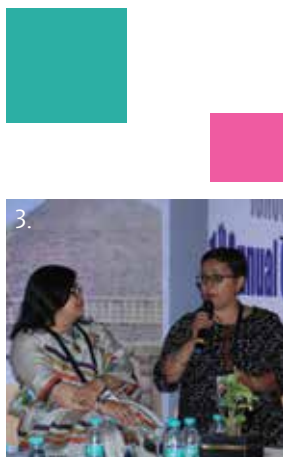
(1) Dr Michael Prados, PNO (2) Dr Rashmi Chaudhary, scientist (3) Neuropathologists (from Left): Drs Kirti Gupta, Geeta Chacko, Chitra Sarkar, Vaishali Suri, Vani Santosh, Jharna Mishra, Namita Chaudhary (4) Kathy and Gordon Oliver (IBTA co-directors) at the IBTA information desk (5) Dr Vinay Puduvalli, USA (6) Registration desk (7) IBTA Co-Director Kathy Oliver at the entrance to the ISNOCON meeting in Bhopal (8) Delegates participating actively (9) Lighting of the traditional lamp (an Indian tradition marking the beginning of an auspicious occasion) during the Inauguration Ceremony





(1) A relaxed evening with music and rendition of the Indian flute by Dr Manish Verma (2) Traditional Indian lunch (3) Delegates in one of the sessions (4) Dr Ching Lau, USA (5) Sharing a light moment (from left): Drs Chitra Sarkar, Geeta Chacko, Tejpal Gupta, Rakesh Jalali (6) From left Dr Harshad Patil, Mr Gordon Oliver, Dr Rajni Chaterjee, Dr Nitin Garg, Dr Renuka Garg, Mrs Kathy Oliver and Dr Puneet Gandhi





(1) Panel discussion on psycho-oncology (from left): Savita Goswami, Kathy Oliver, Prakash Chiotalkar, Rajni Chatterjee, Richa Priyamvada (2) The IBTA's Kathy and Gordon Oliver during an interview with radio jockey Pinki Tiwari (left) (3) Brain tumor survivors at ISNOCON 2019: Dr Sheuli Mitra, left, and Ms Sanjana Rautela, right (4) Dr Tejpal Gupta, Secretary, ISNO (5) Paintings made by pediatric brain tumor survivors handed to the conference organisers (from left): Drs Tejpal Gupta, Nitin Garg, Suresh Sankhla, RK Panday, Rakesh Jalali

From a handpainted original by a Brain Tumour Survivor

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# Every brain tumour patient matters. They count!

Davis F<sup>1</sup>, Smith T<sup>1</sup>, and Brain Tumour Foundation of Canada co-authors

<sup>1</sup>Brain Tumour Registry of Canada, University of Alberta, School of Public Health



The Brain Tumour Registry of Canada (BTRC) has been established in 2019 to ensure that every brain tumour in Canada is counted. Until recently, Canada has relied on data from a number of American and Canadian data resources to guide Canadian research, raise awareness, secure government funding and provide support programs – data that is incomplete and not a true reflection of Canada's brain tumour community.

## Identifying a Framework

This registry, BTRC, was conceived by a committee chaired by Dr. Joseph Megyesi at Brain Tumour Foundation of Canada<sup>1</sup>. Advocacy efforts led by Jennifer Gouchie-Terris (a Canadian patient advocate whose son Brandon was diagnosed with a brain tumour), focused on obtaining complete data to create evidence to support brain tumour policy and research which resulted in the passing of a Canadian House of Commons Bill M235 in February 2007<sup>2</sup>. This bill called for national guidelines for the surveillance of all malignant and benign (non-malignant) brain tumours, but funds were not aligned to accomplish this task. The Public Health Agency of Canada (PHAC) subsequently explored the gap in the collection and reporting of non-malignant brain tumour data and identified barriers to data collection within the provincial and



Dr Faith Davis

territorial cancer registries. At that time, only three of thirteen regional registries formally collected information on non-malignant brain and CNS tumours<sup>3</sup>.

A cancer registration system has been in place in Canada for many years. Provincial/territorial registries are bound by jurisdictional regulations and funding, although each jurisdiction participates in the Canadian Council of Cancer Registries (CCCR) which works to harmonize their efforts and agrees on the type of data to be reported to the Canadian Cancer Registry (CCR). The CCR is compiled from annual provincial/territorial data submissions to Statistics Canada, which provides a data repository creating a national cancer surveillance system. To align with M235 the CCR registry structure was modified to incorporate incoming data on all primary brain tumours and provincial registries began to focus on creating local case ascertainment and data quality processes to allow for the systematic collection of these tumours<sup>3</sup>. PHAC recently demonstrated that data on malignant brain



tumours is well captured in the cancer registry system: national incidence rates are similar to that expected and these rates vary modestly across provinces. In contrast, coverage of the non-malignant tumours is incomplete so that incidence rates based on these data reflect data limitations that complicate interpretation<sup>4</sup>.

In 2012, a collaboration to explore the feasibility of compiling a comprehensive national surveillance report was established between Brain Tumour Foundation of Canada and Dr. Faith Davis, Professor and Vice Dean of the School of Public Health, at the University of Alberta. With the support of five provincial registries and matching funds from Brain Tumour Foundation of Canada, a Brain Canada Platform Support Grant was awarded to create a data infrastructure for such a report.

## Celebrating a Milestone

Now, we are pleased to be able to provide the first incidence report, in partnership with four provincial cancer registries, that speaks to 67% of the Canadian population. This report is the first to incorporate that portion of brain tumours that are non-malignant in Canada. As data on metastases that develop following any primary cancer diagnosis are not available in cancer registries, information on brain metastases

are not included. A further survival report will be released later this year and in 2020 a comprehensive national report will include the entire Canadian population, providing incidence and survival data. We will not stop until every brain tumour is routinely counted, as every brain tumour counts!

Incidence rates for all primary brain tumours from 2010-2015 from four Canadian provinces (BC, AB, MB, ON) can be accessed from this report in English ([braintumourregistry.ca](http://braintumourregistry.ca)) and French ([registretumeurscerebrales.ca](http://registretumeurscerebrales.ca)). Combining this information across provinces makes it possible to provide rates by tumour location, histology, behavior, sex and age.

The most common histology is the primarily non-malignant meningioma which does not routinely get reported in cancer registries. With a few exceptions, incidence rates for primary brain tumours are more common in males than females and increase with age. It is important to note that tumour histology varies by age and sex: young children (0-4 years) commonly develop embryonal tumours; children (5-14) commonly develop pilocytic astrocytomas; young adults commonly develop tumours of the sellar region; adult males commonly develop GBMs and adult females commonly develop meningiomas. When applied to the projected Canadian population, these incidence rates allow us to estimate the number of new cases of primary brain tumours that will be diagnosed in Canada in 2021.

## One Step Closer

While this report is an important step forward, there is much work remaining to achieve the high-quality data envisioned. Cancer registries in Canada continue to search for ways to improve case ascertainment for non-malignant tumours and this incidence report shows rates of “unclassified” tumours that are higher than expected, a finding requiring further exploration. BTRC will continue to support provincial registries in their efforts to improve data quality.

Our hope is, that by counting every brain tumour in Canada, we will get one step closer to finding the cause of and prevention for all brain tumours. We hope to improve the availability of accurate, complete, and analyzed data of malignant and non-

malignant brain tumours in the Canadian population. This data is necessary to secure increased funding for research, health-care delivery, and drug approval by Canadian federal and provincial agencies.

Our appreciation is extended to every individual Canadian this information represents.

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# Two Sons with a Rare Brain Cancer?

## We Choose to Fight Through Advocacy

**Brock Greene**

Founder of Oligo Nation, United States



*Read how a father is advocating to save his two sons with oligodendrogliomas and how his family copes*

Like most oligodendroglioma patient stories, ours started with the shock of the diagnosis on 1st August 2008. Our 16-year-old son, Spencer, was experiencing focal seizures in his right arm when he played soccer. After months of eliminating possible causes, an MRI confirmed a brain tumor called an oligodendroglioma the size of a lemon in his right frontal lobe.

Two days later, Spencer had surgery to remove as much of the tumor as possible. We spent the next 20 months doing the MRI thing, hoping that the tumor would stay quiet for a long time. In April 2010, he had another focal seizure and was put on chemotherapy for a year.

In June, before Spencer started temozolomide, an oral chemotherapy drug, we took a family vacation to Mexico. A few hours after arriving, our older son, Zach, then age 21, had a grand mal seizure. It was the scariest experience of my life. We returned home and the MRI revealed that Zach also had an oligodendroglioma. Fortunately, neurosurgeons removed "all" of his tumor.

As with most oligodendroglioma survivors, the medical story didn't end there – far from it. Since then, both boys have had a recurrence and a second surgery followed by proton therapy and chemotherapy. And more recently, Spencer's MRI showed apparent growth, so he has been on a clinical trial targeting the IDH1 gene, for about a year. Both boys are on the ketogenic diet.

But, we are lucky. Both boys are doing well and living their lives with few limitations – other than having to live near a top brain tumor center. Zach recently received his doctorate in physics from Columbia University in New York and is looking to put all that knowledge to work. Spencer lives in the San Francisco Bay area and works for a healthcare provider.



Brock Greene is the father of Spencer and Zach, who have both been diagnosed with oligodendrogliomas

### The Personal Journey

I don't honestly think there's a way for others to really understand what something like this does to your life and outlook. The

grieving process often begins at diagnosis. And going through the five stages of grief isn't pretty – and I doubt I will ever get to 'acceptance.' Over time, I have found it possible to be positive and continue to lead a full life, but there's no escaping the sense of dread of the future.

And our family has gotten better at dealing with our reality. At the beginning, we didn't understand much about this disease, and we were somewhat afraid to find out more. Each new medical setback would plunge us into the fearful unknown. But we came to accept that in one way or another, we would find our way through it.

Without a doubt, the biggest factor in our coping with and, to some extent, overcoming the negatives of our situation has been the work we have done with Oligo Nation to advance research. Instead of feeling helpless in the face of a currently incurable disease, we are energized and excited about the progress and opportunities



The Greene boys, 2012, from left to right: Spencer, Zach and Brock Greene



The boys (left: Zach and right: Spencer) and their mom, Pam, Thanksgiving 2017

ahead. Two years ago, I moved from hopeful to optimistic, which might not sound like much, but it is a huge difference.

On a different level, the support we have received and continue to receive from friends, family and others has been beyond belief. Our family is amazed and humbled by the love that we feel.

The final thing is that I know that we are lucky. Both our boys are alive and (mostly) well. Being grateful for what we have is more powerful than grieving over what we have lost.

### Getting Involved

Having two kids with brain cancer was more than I could handle initially. But after a few months, I picked myself up

off the floor. I remembered my father's saying: "Greenes don't take bad news lying down." I realized I had to do anything and everything in my power to "save" my boys.

But where to start? I donated to a brain tumor foundation. Then, I checked their website and realized they weren't funding any oligodendroglioma research. I checked other brain tumor foundations – no oligodendroglioma research. So, I called to see what could be done. They told me that they would create a dedicated oligodendroglioma research fund. We were successful in raising money over three years, but, ultimately, it was clear to me that this foundation was not going to solve our problem.

Believe me, it was never our plan to run our own non-profit. But in early 2014,

I jumped in all the way and created Oligo Nation. It was going to have to be the vehicle to deliver the new treatments my family and thousands of others needed. A priority was to get others in the oligodendroglioma community involved in fundraising to support research and advocacy.

It took us several years to build up our war chest, but in 2016, we started making grants for medical research. Over the past few years we have made 14 grants and have raised the visibility of oligodendroglioma research with leading institutions. Having money to invest is critical, but a lot of good things have happened by just asking, "How does your work apply to oligodendroglioma?"

There is one other area that has been of increasing importance – acting as a resource for others in the oligodendroglioma community as they try to navigate a difficult and sometimes confusing landscape of treatment options, second opinions, and insurance hurdles.

My family is committed 100%, every day of the year. That's why we are excited to partner with the National Cancer Institute's new program called NCI-CONNECT, which is focusing on selected rare adult central nervous system cancers, including oligodendroglioma. I believe that combining efforts by NIH, non-profits, and research institutions is an approach that will have a positive impact on improving care and treatment for patients. ■

**Two Sons with a Rare Brain Cancer? We Choose to Fight through Advocacy** was originally published by the National Cancer Institute on the NCI-CONNECT Rare Brain and Spine Tumor Blog at [cancer.gov/nci-connect](http://cancer.gov/nci-connect).

To find out more about Oligo Nation visit [www.oligonation.org](http://www.oligonation.org) or email [brock@oligonation.org](mailto:brock@oligonation.org)



After Zach's surgery in 2010, with Spencer (right)

**Plan your 2019 "Walk Around the World for Brain Tumours" now!**

For further information, contact [kathy@theibta.org](mailto:kathy@theibta.org)



# GLIOTRAIN Study update: meet our fifteen talented young GBM researchers

Compiled by Dr Alice O'Farrell  
GLIOTRAIN Research Programme Manager,  
Royal College of Surgeons in Ireland



*In our last edition of Brain Tumour magazine, we introduced readers to the exciting international GLIOTRAIN project focused on glioblastoma research. Here, the GLIOTRAIN consortium (led by Prof Annette Byrne of the Royal College of Surgeons in Ireland) brings us up-to-date on the project's activities over the past twelve months.*

It has been one year since we last reported on the GLIOTRAIN project ([www.gliotrain.eu](http://www.gliotrain.eu)), an EU funded Marie Skłodowska Curie Innovative Training Networks (ITN) award recipient coordinated by the Royal College of Surgeons in Ireland. This major research initiative aims to train the next generation of brain cancer researchers. The project has received funding of almost €3.9 million from the European Commission's Horizon 2020 Research and Innovation Framework Programme and commenced in September 2017. The Programme is now well underway and we are pleased to bring you a study update, whilst introducing you to

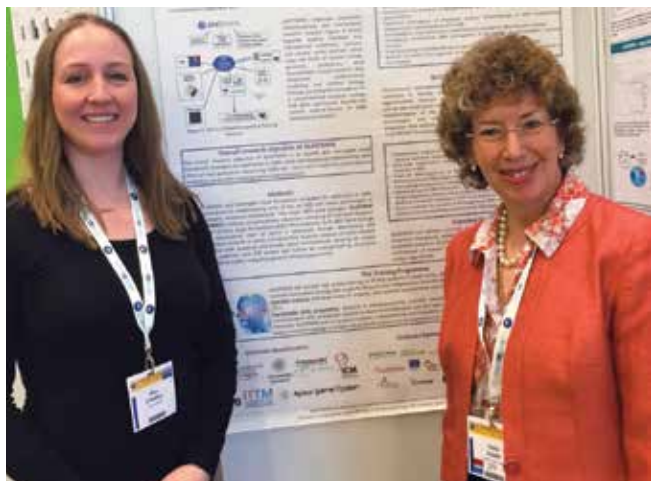
the 15 PhD students who are funded under the Programme.

Glioblastoma (GBM) is the most common and aggressive form of adult brain cancer. Newly-diagnosed patients who receive standard of care (surgery, radiation therapy and temozolomide chemotherapy) still have insufficient life expectancy, largely as a result of tumour re-growth after surgery, and the subsequent development of tumour resistance to treatment. Therefore it is vital that new treatments for GBM tumours be developed in order to address the poor outcome for GBM patients. This can only be achieved by focused multi-sectoral industry-



The fifteen PhD students working on GLIOTRAIN come from all around the world and as described in the following pages are located in laboratories across Europe. Pictured are (left to right): Mohammed Ahmed (Palestine), Ayoub Lasri (Spain), Chiara Boccellato (Italy), Federica Fabro (Italy), Jenny Weng (China), Gonca Dilcan Durdag (Turkey), Archita Biswas (India), Viktorija Juric (Croatia), Ioannis Ntafoulis (Greece), Manasa Kalya Purushothama (India), Francesca Lodi (Italy), Kieron White (UK), Romain Tching Chi Yen (French Polynesia), Yahaya Yabo (Nigeria) and Nivetha Krishna Moorthy (India).





Dr Alice O'Farrell (left), GLIOTRAIN Research Programme Manager, Royal College of Surgeons in Ireland and compiler of this article. Alice is pictured with IBTA Chair Kathy Oliver (right).

academia collaborations in newly emerging, innovative research disciplines. The research objective of GLIOTRAIN is to identify novel therapeutic strategies for treating GBM patients, while implementing state of the art methods to unravel disease resistance mechanisms. In ITN networks, each student takes on an individual research project, with its own aims and objectives, however all 15 projects are linked by a common endeavour to improve the treatment and understanding of GBM. Ultimately the aim of GLIOTRAIN is improved patient outcomes from this most difficult to treat disease.

In the following paragraphs you will be introduced to our 15 students and also read about their individual PhD projects.

### GLIOTRAIN Work Package One

The programme is split into two "work packages": Work package one is focused on the development of new treatment options for GBM. There are eight projects within this work package.



**Viktorija Juric** is based at the Royal College of Surgeons in Ireland (RCSI) under the supervision of Dr Brona Murphy. Viktorija's GLIOTRAIN project focusses on investigating a group of drugs called "Cyclin-dependent kinase (CDK)-inhibitors". CDKs are enzymes critical in regulating cell growth and development. Virtually all cancer cells, including those in

GBM, harbour alterations that lead to the over-activation of CDKs, resulting in the proliferation of cancer cells. Drugs that inhibit CDKs are currently used for the treatment of breast cancer and are studied in many other types of cancer. To date in this project, using newly diagnosed and recurrent GBM cell cultures, Viktorija has demonstrated the potential of CDK inhibitors to significantly decrease GBM cell viability. Viktorija is currently combining these inhibitors with other anti-cancer drugs to identify clinically relevant approaches for treating GBM.



**Chiara Boccellato** is based at the University of Stuttgart in Germany under the supervision of Prof Markus Morrison. Chiara's GLIOTRAIN project focusses on developing new, more specific drugs for GBM treatment. The rationale is that each GBM tumour is different to another and therefore we should expect different sensitivity to different drugs. The standard chemotherapy drug for newly diagnosed

GBM treatment is temozolomide and this provides relatively little survival benefit and generally only to a particular subset of patients. The result of administering the same drug to everyone is lack of patient-specificity; each GBM case has a different profile ("tumour heterogeneity") and therefore patient pre-selection would avoid the administration of ineffective drugs. To investigate this, Chiara is assessing a panel of GBM cells for their responsiveness to a type of drug that induces cell death. She will then verify if the *in vitro* results about sensitivity or resistance are in accordance to the predictions generated by a mathematical model that has been developed at the University of Stuttgart. In the era of personalized medicine, if this mathematical model can be validated, it could become a cheap and fast instrument for clinicians to select the best treatment option for individual GBM patients.



**Nivetha Krishna Moorthy** is from India and is also based at the University of Stuttgart under the supervision of Prof Morrison and Dr Gavin Fullstone. Nivetha's project is focussed on the development and testing of a new drug variant that can penetrate into brain tumours. The blood brain barrier (BBB), usually there to protect the brain, is a major limitation for the penetration of

some drugs (mainly those with a large molecular structure) into GBM tumours. Nivetha hopes to develop a variant of a type of drug called "TRAIL". TRAIL works by "instructing" cancer cells to die, however in its current form cannot travel effectively through the BBB. She hopes that the new variant of the drug will have chemical properties enabling it to be delivered to the tumour, successfully getting through the BBB. So far Nivetha has purified a new drug variant and is currently optimising an *in vitro* test for the drug, using both GBM cells and cells that make up the BBB. Nivetha hopes that if the new variant can successfully get through the BBB this will improve its efficacy against GBM tumours.



**Mohammed Ahmed** is from Palestine and is based at the Institute of the Brain and Spinal Cord in Paris, France under the supervision of Dr Ahmed Idhahbi and Dr Maite Verreault. As previously mentioned, the BBB inhibits the penetration of some drugs into the brain and thus the GBM tumour. One way of overcoming this problem is to use methods that mechanically "open"

the BBB, allowing drug delivery. One such method involves the use ➤

of ultrasound waves. Ultrasound mediated-BBB opening (UMBO) may help to increase the biological and therapeutic impacts of some drugs in GBM. One example would be the immune checkpoint inhibitors (ICIs), which have improved the prognosis of some solid tumours (e.g. melanoma, lung cancer). The effect of ICIs in GBM is still under investigation, but without the opening of the BBB, the passage of these drugs to the tumour is not sufficient for a therapeutic effect. Mohammed will assess the brain penetration of ICIs and their effectiveness alone or with UMBO in preclinical GBM models. Mohammed hopes that his project will be transferable to the clinic in the coming years and that ICIs might show efficacy in GBM tumours.



**Kieron White** is the second student based at RCSI and is under the supervision of Prof Annette Byrne (GLIOTRAIN Coordinator). Currently, GBM can be classified into three subtypes; proneural, classical and mesenchymal. Each subtype displays a difference in response to therapy, due to specific characteristics carried within the tumour microenvironment

(TME). The aim of Kieron's project is to identify new vulnerabilities in different subtypes of GBM. Initially, Kieron will perform transcriptomic profiling on GBM samples (taken from patients and currently held in biobanks). This gene expression data will be used to accurately infer immune (white blood cells) or stromal (e.g. blood vessels) content of the patient samples. Different types of drugs can target different areas of the tumour so this information will be used to inform which drugs might work in one type of tumour compared to another. New treatment hypotheses will be tested in preclinical models, which are closely representative of GBM tumours in patients. The prospective outcome for this project is that it will potentially inform new and more precise treatment options for GBM subtypes.



**Linqian (Jenny) Weng** is from Beijing, China. She is now based at VIB-KU Leuven in Belgium under the supervision of Prof Gabriele Bergers. As previously discussed, GBM is the most common primary brain tumour in adults and it is eventually resistant to almost all kinds of therapies (including chemotherapy, radiotherapy and targeted therapy). This is due

to GBM being heterogeneous - it is not only different between different patients, but also different in separate regions inside one patient's tumour. Inside the tumour, all the mutated tumour cells and supporting cells (e.g. blood vessels, immune cells) are "working" together to maintain the growth of the tumour. In her project, Jenny will investigate how all these cells are actually "working" and interacting together, and how this affects the way in which they will respond to therapies. To answer these questions, Jenny is generating a novel GBM preclinical model that can mimic

the heterogeneous human GBM. The model will be used to investigate why GBM is resistant to therapies, hopefully indicating potential new avenues of treatment modalities.



**Ioannis Ntafoulis** is from Greece and is currently studying for his PhD at Erasmus Medical Centre in The Netherlands under the supervision of Prof Martine Lamfers. His research is focused on drug repurposing of anti-cancer agents for personalised treatment of GBM. Drug repurposing is the process of evaluating if currently approved drugs, used to treat other illnesses, would work in a different disease, in this case GBM. In his project, Ioannis has tested 114 registered anti-cancer agents on a number of GBM patients' cell cultures. Systems medicine approaches have also been implemented to assess correlations between drug response and molecular characteristics of the original GBM tumours from which the cells were derived. In the future Ioannis hopes that this could lead to a new test to see which medicine would be most appropriate for individual patients. Importantly, drug repurposing can lead to considerable shortening of the testing phase of the drug development life cycle, ultimately reducing the cost of treatment and providing new therapeutic options for GBM patients.



**Gonca Dilcan Durdag** is originally from Turkey and is undertaking her GLIOTRAIN PhD in the Genomics Division of Agilent Technologies in Belgium under the supervision of Prof Jurgen Del Favero. Currently, non-invasive imaging approaches such as magnetic resonance imaging and CT scans are used to diagnose GBM. However, none of these imaging

techniques are able to identify tumour heterogeneity; one of the main obstacles for diagnosis and treatment, as it results in different treatment responses and outcomes. Therefore, novel non-invasive tests which are able to detect minor differences in tumour behaviour are urgently needed to complement these existing options. Recent advances in sequencing technologies allow us to uncover the genetic code in cancer patients and use this information to identify biomarkers that can direct tumour diagnosis and treatment. A biomarker is a molecule found in bodily fluids that reflects the severity or presence of a disease. Gonca's project aims to design GBM specific biomarker tests that will enable early diagnosis and continued disease monitoring.

### GLIOTRAIN Work Package Two

Work package two focusses on improving the understanding of GBM therapy resistance. This is a key issue that must be investigated in order to improve patient outcomes due to the fact that drug resistance leads to treatment failure and disease recurrence. There are seven projects in this work package.



**Archita Biswas** is the third student based at RCSI and is under the supervision of Prof Jochen Prehn. Archita is from Kolkata, West Bengal, India. The objectives of Archita's project are to investigate the differences in the DNA, RNA and proteins of GBM tumours in short-term survivors compared to long-term survivors of GBM, asking the

questions: "Why do some patients have a better prognosis than others? What makes them different? Can we use this knowledge to improve treatments for patients?" The DNA, RNA and protein data from each group will be entered into computer models, where systems modelling techniques will be applied to analyse the huge amount of data. Archita will generate a "signature" that identifies each group of patients, with the overall aim of identifying druggable vulnerabilities for GBM patients with 'poor' prognoses. Archita hopes that the project will lead to the development of refined prognostic signatures for GBM.



**Ayoub Lasri** is the fourth student based at RCSI and is under the supervision of Dr Marc Sturrock. Ayoub is a mathematician and in his GLIOTRAIN project uses mathematical tools to understand how GBM cancer cells become resistant to chemotherapy. Specifically, he uses mathematical equations to describe what is happening within a cancer cell before

and after the administration of chemotherapy, in order to have a clear idea about the mechanisms responsible for the emergence of resistance. So far, Ayoub has shown that the random nature of some intracellular processes may be sufficient to explain the development of resistance to chemotherapy. His next step will be to add complexity to the model, making it as close as possible to a real-life tumour. Ultimately, Ayoub hopes to identify possible ways to overcome the resistance of GBM tumours to chemotherapy.



**Francesca Lodi**, from Italy, is the second student based at VIB-KU Leuven in Belgium and is supervised by Prof Diether Lambrechts. As previously mentioned, one of the main features of GBM is heterogeneity. Unfortunately, it is very difficult to fully recapitulate this heterogeneity in model systems. Within GLIOTRAIN, Francesca focuses on interrogating GBM heterogeneity,

specifically in the context of the TME, thus gaining insights into the complex network of cells' interactions and how this can change under the pressure of therapy. To achieve this, Francesca applies innovative technologies of next generation sequencing at the individual cell level to human and murine GBM tumours, hopefully leading to the design of promising future diagnostic and therapeutic strategies for GBM patients.



**Yahaya Yabo**, from Nigeria, is based at the Luxembourg Institute of Health under the supervision of Prof Simone Niclou and Dr Anna Golebiewska. Yahaya's PhD project focuses on the diversity of GBM cells and its impact on resistance to treatment. He works with preclinical models using tissue derived from patients' tumours. These models can be used for genetic analysis of GBM as well as for testing conventional

and new drugs. During the first months of his PhD, Yahaya analysed GBM cells growing in preclinical models and observed an excellent similarity with molecular profiles (i.e. expression of genes) present in human tumours, indicating that the model is a good representation of the human disease. With the use of new powerful sequencing techniques applied to individual cells, Yahaya has further revealed a wide molecular diversity (heterogeneity) present in his preclinical GBM models. In further experiments, he will examine the effects of conventional treatments on selection and plasticity in his GBM tumour models. Yahaya hopes that this project will improve the knowledge of tumour resistance mechanisms, which may allow for development of more efficacious drugs in the future.



**Federica Fabro** is from Italy and is the second student undertaking her PhD at Erasmus Medical Centre in The Netherlands. Federica is under the supervision of Dr Sieger Leenstra. The problem of drug resistance is not only related to the GBM standard of care drug temozolomide, but also for newly emerging medicines, including a category of drugs called "small kinase inhibitors",

which despite showing promising preclinical results, did not lead to improved patient outcomes in the clinic. The concept for Federica's project is the assumption that GBMs are different between patients and therefore so are the mechanisms leading to resistance. The aim of Federica's project is to prove this last concept and discover new personalized possibilities for treatments to overcome resistance. Federica will use small pieces of patients' tumours, treated with small kinase inhibitors *in vitro*, and will sequence them before and after treatment to discover the mechanisms that lead to resistance. Using tumour tissue in this way preserves the "personal" genetic features of the human tumour, making the technique clinically relevant. Overall, the ultimate goal is to translate the results to the clinic and thus to target resistance before it occurs, improving the outlook of GBM patients.



**Manasa Kalya Purushothama** is from India and is based at geneXplain GmBH in Germany under the supervision of Dr Alexander Kel. Biologically aggressive GBM tumours present unique treatment challenges due to chances of recurrence. The main reason is "therapy resistance"; the mechanisms underpinning this are not well understood. Despite more than 60 trials of newly developed targeted ➤





Pictured: The GLIOTRAIN Consortium (left to right): Francesca Lodi, Dr Alexander Kel, Dr Andreas Kremer, Dr Alice O'Farrell (GLIOTRAIN Programme Manager), Prof Jochen Prehn, Dr Brona Murphy, Prof Diether Lambrechts, Prof Reinhard Schneider, Prof Jurgen Del Favero, Dr Marc Sturrock, Prof Markus Morrison, Ioannis Ntafoulis, Dr Anna Golebeiwski, Yahaya Yabo, Prof Annette Byrne (GLIOTRAIN Coordinator), Kieron White, Nivetha Krishna Moorthy, Federica Fabro, Ms Kathy Oliver (IBTA), Dr Jeroen de Vrij, Archita Biswas, Prof Sieger Leenstra, Manasa Kalya Purushothama, Romain Tching Chi Yen, Jenny Weng, Gonca Dilcan Durdag, Ayoub Lasri, Dr Maite Verreault, Dr Ahmed Idbaih, Viktorija Juric, Prof Monika Hegi (GLIOTRAIN External Advisory Board member), Mohammed Ahmed, Chiara Boccellato

drugs tested in recurrent GBM, no drugs have shown survival benefits and this is a critical issue in patient care. The advent of next generation sequencing technology and multi-'omics (techniques to look at changes in DNA, RNA and proteins) has led to the availability of huge GBM tumour databases. The goal of Manasa's project is to convert this huge amount of data into biological insight for better treatment strategies. Manasa's research aims to develop computational models of GBM by integrating different 'omics technologies through which mechanisms of GBM drug resistance can be revealed, modelled and targeted. Manasa hopes to be able to model disrupted cell mechanisms responsible for therapy resistance and to identify prospective drug targets for therapeutic intervention.

understand how the tumour can become resistant to treatments, and hopefully find ways to overcome that resistance.

### Important groundwork laid

In conclusion, as you can see from the work described above GLIOTRAIN is well underway, and in the first year since recruiting our students, important groundwork is being laid upon which the projects will build. We look forward to bringing you these updates over the coming years.

Finally, we would like to extend our gratitude once again to the IBTA and Kathy Oliver for their constant and compassionate support of both the Programme and also of our students. ■



The final GLIOTRAIN project is that of **Romain Tching Chi Yen**. Romain is from Tahiti and now is undertaking his PhD at ITTM, in Luxembourg, supervised by Dr Andreas Kremer. His project has two main objectives. The first is to create a "GBM Disease Map", a graphical network representation of what science knows about the molecular

mechanisms of the disease - that is to say how proteins and/or genes behave abnormally, interact with each other and how that leads to GBM. That will not only allow for a good overview of the disease, accessible even to new researchers in the field, but also may provide new insight on the mechanisms of the disease, as it brings together multiple sources of information into one place. Secondly, Romain will perform Statistical and Machine Learning analyses utilising the wealth of data produced by the other GLIOTRAIN PhD students. In combination with analysis of the Disease Map, he intends to use this multi-platform approach to

The IBTA is delighted to be a partner organisation in the GLIOTRAIN project. We're particularly thrilled to see such an energetic, inspirational and determined international group of young, early researchers entering the glioblastoma space. It's crucial that this disease area attracts new, enthusiastic researchers who bring fresh approaches and ideas to the study of glioblastoma. Seeing these young researchers hard at work on improving outcomes for GBM patients and their families is very exciting and hopeful. We look forward to bringing you further updates on the students' findings and discoveries as the GLIOTRAIN programme evolves.

For more information on GLIOTRAIN and for regular updates on what the students are up to please visit: [www.gliotrain.eu](http://www.gliotrain.eu) or follow them on Twitter (@gliotrain) and Facebook (@GliotrainEU).

## KEY VOCABULARY

**DNA:** Deoxyribonucleic acid, or “DNA” carries the genetic instructions (or “genetic code”) used in the growth, development, functioning, and reproduction of all known living organisms. DNA is a sequence of four small components (known as A, G, C and T). Even small differences in the sequence can lead to defects in cells and to disease. These differences are called mutations.

**RNA:** Ribonucleic acid, or “RNA” translates the DNA into actual processes in a cell or organism, by “translating” the genetic code into proteins. Mutations in the machinery of RNA can also lead to disease states.

**Proteins:** These are large molecules present inside cells that carry out the instructions given by the DNA. They are essential parts of organisms and participate in virtually every process within cells. Many proteins are enzymes that catalyse biochemical reactions and are vital to metabolism. Other proteins are important in cell signalling, immune responses, and the cell cycle. As with DNA and RNA, small changes in protein structure can have a large effect on its ability to perform. Such changes can therefore also lead to disease.

**Enzymes:** A class of protein, folded into complicated shapes; they are present throughout the body. Enzymes speed up (catalyze) chemical reactions and in some cases, enzymes can make a chemical reaction millions of times faster than it would have been without it.

**Cell proliferation** is an increase in the number of cells, as a result of cell growth and cell division.

**Cell viability** is defined as the number of healthy cells in a sample i.e. whether the cell is viable for life. A cell viability assay determines the percentage of cells that are living or dead in a sample.

**In vitro:** refers to the technique of performing experiments in a controlled environment outside of a living organism, in a laboratory.

**Cell culture:** An *in vitro* technique, where cells taken from glioma patients’ tumours are grown in a lab (in plastic flasks).

**The tumour microenvironment (TME):** The TME is the cellular environment in which the tumour exists, including surrounding blood vessels, white blood cells and other cells which interact with the tumour. This complex cellular ecosystem contributes to the diversity (heterogeneity) shown by GBM tumours.

**Tumour heterogeneity:** Tumours (including GBMs) can differ between patients (inter-tumour heterogeneity), however one tumour can also show vast differences in separate areas of the same tumour (intra-tumour heterogeneity) in the same patient.

**Tumour plasticity:** This inherent feature of tumour cells allows them to change their form and/or function (mutate) upon

treatment or changes in the environment surrounding the tumour cells. This can lead to drug resistance.

**Blood-brain barrier (BBB):** The BBB is a barrier, made up of tightly knit cells surrounding blood vessels in the brain. Usually this barrier protects the brain from harmful chemicals and pathogens, however it also prevents or seriously hinders larger drugs from reaching brain tumours.

**Preclinical models:** Preclinical models are a stage of research that takes place before any testing in humans. It covers an array of techniques ranging from basic cell models through to animal models. It is important that preclinical models replicate the human disease as closely as possible to make sure results are as translatable as possible. Animal models (such as mice, which are called murine models) are included in the definition of preclinical models and are currently the closest model that scientists have to replicating the human disease, as it represents a whole organism.

**Mathematical model:** This is a description of a complex system (like a cell) using mathematical language. A model helps to explain a system, to study the effects of different components and to make predictions about behaviour, for example about resistance or sensitivity to a certain drug. The benefit of a mathematical model is that you can adjust one part of the system to see its effect on another part.

**Systems medicine:** This technique involves computational, statistical, mathematical analysis and modelling of disease mechanisms, disease progression and remission, disease spread and cure, treatment responses and adverse events as well as disease prevention both at the population and individual patient level.

**Next generation sequencing (NGS):** Basic sequencing includes all techniques to discover the order of A, G, C and T in the DNA or the equivalent in RNA. NGS encompasses the newer methods for sequencing, developed at the end of 1990s, revolutionizing genomic research. In comparison to the traditional strategies, it is much quicker, cheaper and allows the entire genome to be sequenced at once in an automated process. NGS gives us information about the changes in genes and indicates new biomarkers that can direct tumour diagnosis and treatment.

**Statistical and machine learning analyses:** They are methods commonly used in research to explore and make sense of the huge amount of data created by the NGS technologies, using statistics or complex mathematical algorithms to identify interesting characteristics of the data.

**Transcriptomic profiling:** Transcriptomic profiling is the measurement of genes present within a cell or population of cells. Analysing the genes expressed (by looking at changes in RNA) can help determine the function of the cells and the response to different treatments.

# The International Low Grade Glioma Registry 2019

**G**lioma is the most common primary malignant brain tumor in the United States. One of the biggest knowledge gaps in neuro-oncology is how to best manage patients with low grade - World Health Organization (WHO) grade II - glioma (LGG). Survival for this relatively young group of patients has not significantly changed over the past forty years and the optimal means by which these patients should be treated remains a much debated topic in neuro-oncology.

This lack of information lead Elizabeth B. Claus, M.D., Ph.D., Professor and Director of Medical Research at the Yale School of Public Health and Attending Neurosurgeon at Brigham and Women's Hospital, to begin the International Low-Grade Glioma (LGG) Registry, a global effort to study adult LGG. The LGG registry is using web- and smartphone-based recruitment methods to create a large, collaborative database for researchers to learn more about the best treatment choices for LGG as well as to gain information on how to maximize quality of life and neuro-cognitive function. Enrollment into the registry is via the Internet and thus is open to patients throughout the world.

Participants who have undergone surgery are asked to submit a pathology report to confirm eligibility and are then asked to complete a short online questionnaire as well as provide a saliva sample (sent via the mail). Patients who have not yet had surgery, oftentimes because their lesion is in a difficult-to-reach location such as the brainstem, may submit an MRI picture in place of a pathology report.

An introductory video on the study is available at <https://www.youtube.com/watch?v=cbF5LpIY5dA>

The study is funded by the American Brain Tumor Association (ABTA), the National Brain Tumor Society (NBTS)) and the LOGLIO collective. New funding



Elizabeth Claus, PhD, MD, Professor and Director of Medical Research at the Yale School of Public Health (New Haven, Connecticut) and Attending Neurosurgeon at Brigham and Women's Hospital (Boston, Massachusetts, United States)

was obtained this year from The Netherlands through the generosity of <https://stophersentumoren.nl/> (STOPhersentumoren.nl).

In an effort to reach additional participants, the LGG registry took to social media this year via Twitter (@gliomaregistry) and Facebook (<https://www.facebook.com/gliomaregistry>). Excitingly, these social media efforts brought in a number of international participants, notably from Australia and The Netherlands, as well as the first participants from South America and Hungary.

Dr. Claus said: "To date we have enrolled approximately 300 patients, with participants from 21 states in the US and twelve countries including the US, France, United Kingdom, Canada, Australia, Hong Kong, New Zealand, Belarus, The Netherlands, Belgium, Germany and Spain."

The LGG registry also entered into an important partnership with the National

Cancer Institute (NCI) this year, via the new NCI-CONNECT program. This program will permit an increased focus on a number of rare tumors of the central nervous system, including oligodendroglioma, the most commonly reported type of adult LGG.

"The NCI-CONNECT program for oligodendroglioma is so important," said Dr Claus, "and its support of our registry, including assistance with tumor genotyping, allows us to move forward to study this disease. It has also been a great way to meet with other groups studying glioma allowing us to increase collaboration and avoid duplication of effort with other investigators."

To reach the study goal of 2000, Dr. Claus and her team of student volunteers at Yale University and Brigham and Women's Hospital are seeking additional people living with LGG to participate. Participation in this global effort will bring much needed research to foster better understanding of LGG, create more effective treatments, and improved symptom management for this tumor type. ■

To join the registry or learn more, visit the study website at <https://lggregistry.wixsite.com/study>, email [glioma@yale.edu](mailto:glioma@yale.edu) or scan the following QR code:





### Commonly Asked Questions:

**Q. The LGG study asks for a pathology report to confirm eligibility. How do I get such a report?**

**A.** Many patients already have such a report at home. If not, patients can either ask their neurosurgeon for a copy or request a copy from the medical records department of the hospital where the surgery was performed. Now that many hospitals have electronic medical records, patients may also gain access to their pathology report by signing up online to look at their medical record.

**Q. If I was initially diagnosed with a grade II glioma but am now diagnosed as a higher grade glioma (III or IV), am I still eligible for the study?**

**A.** Yes. The only requirement is that the initial tumor be grade II. In fact, enrolling patients with pathology collected at multiple time-points is very important to the study as it allows us to examine whether genetic mutations in LGG tumors stay the same or change over time. It also allows us to see how treatment (radiation and/or chemotherapy) may be associated with changes in genetic mutations within the tumor. This information may be used to better guide treatment if a tumor recurs.

**Q. I have a family member or friend who has been diagnosed with LGG and who would like to join the registry but has difficulty using the computer. May I help them to join?**

**A.** Yes - as long as that person has given permission for you to help them.

**Q. I don't have a computer but would like to join the registry. Is this possible?**

**A.** Yes. To reduce costs, we are encouraging registrants to use the Internet whenever possible but we do offer other options, including via mail, fax, and smartphone. There are no costs to you for participation if you send the consent and your pathology report via the secure Yale website [glioma@yale.edu](mailto:glioma@yale.edu). If you decide to send the consent and/or your pathology report via mail you will need to obtain a stamped envelope to mail these items to Dr. Elizabeth B. Claus, School of Public Health, Yale University, 60 College Street, New Haven, CT 06520-8034, USA. You may also fax your materials to + 1 203-785-6912. Our telephone contact is + 1 203-785-6415. Our team is available to help you to determine the best way for you to participate.

## Working and walking for brain tumour patients in Ireland

Cliona Doyle

Brain Tumour Ireland

OVER 400 people came along to the annual Brain Tumour Ireland run/jog/walk event in Dublin in November 2018 and a great day out was had by all!

Aside from being an important fundraiser for the work of Brain Tumour Ireland, the mileage we covered together contributes to the symbolic "Walk Around the World for Brain Tumours" as part of the annual International Brain Tumour Awareness Week.

Chloe Watkins and Nikki Evans from Ireland's heroic hockey world cup silver medal team were on hand to do the pre-race warm up. They generously gave their time and were a real inspiration to all the kids with their world cup medals. For the first time ever the main event was also preceded by a special kids race which was really popular with the younger generation.

The funds raised on the day will help support brain tumour patients and their families in Ireland, as well as contributing towards medical research into brain tumours. ■

**For further information about Brain Tumour Ireland, please visit [www.braintumourireland.com](http://www.braintumourireland.com)**

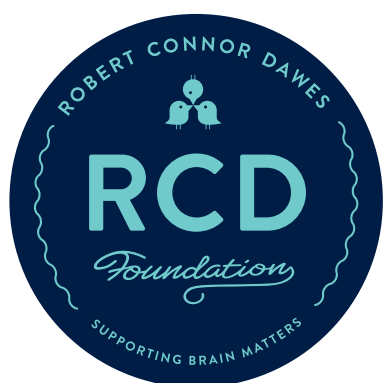


Memories of the Brain Tumour Ireland run/jog/walk event in Dublin in November 2018

# Aiming high - the Robert Connor Dawes Foundation

## Liz Dawes

Founder and CEO, The Robert Connor Dawes Foundation, Australia and the United States



Connor was the eldest of our three children, his full name: Robert Connor Dawes.

When Connor was just four, his brother Nick two and his sister Hannah six weeks, we moved our family to Wellington, New Zealand for my husband Scott's job. After 18 months, in December 1999, we moved again, this time to Melbourne, Australia.

Connor was a bright, quirky child. In high school - apart from academics which he easily excelled at - his passion was rowing. Connor was determined to study and row at either the University of Wisconsin (his birthplace) or Stanford University in the United States. He was awarded a young scholar diploma and invited to join Stanford summer school. Just days after receiving his invitation letter, Connor, then 17 was diagnosed with an anaplastic ependymoma. Dreams of attending Stanford were quickly replaced with facing this unwelcome monster. It was 12th December 2011.

Major surgery caused loss of movement to Connor's right side, impaired vision and severe short-term memory loss. But while his body was broken, his spirit was not. Determined to improve, Connor spent hours each day on his physical and mental rehabilitation. More treatment followed. Throughout it all, Connor never stopped smiling. He stayed positive,



Liz Dawes of the Robert Connor Dawes Foundation

philosophical and true to his yoga affirmation: "I will be awesome."

For 16 months, Connor's brilliant mind, strong body and gentle soul faced off against an ependymoma. Like many others, his brains and brawn gave it all against the poor odds. But on 20th April 2013, Connor's own battle ended. Inspired by his love of Latin he helped us coin the phrase *aeternum fortis*, meaning "eternal strength" and in this spirit we created the Robert Connor Dawes Foundation as a tribute to him and other young people going through brain cancer.

Since its formation, our foundation has been on a mission to fund crucial research projects to improve treatment options, support young patients with at-home rehabilitation like music therapy, and inspire and fund the next generation of brain cancer practitioners and researchers through development initiatives.

### AIM BRAIN Project

The AIM BRAIN project helps doctors better understand individual types of tumours



Connor Dawes with a puppy from the family dog's litter

using genomics-driven methylation arrays. This Australian-first RCD Foundation initiative provides access to world-leading research technology led by Dr Stefan Pfister at the German Cancer Research Centre (DKFZ). With this clearer understanding of each tumour, specialists can create better, personalised treatments not just based on tumour type, but on its actual molecular build. This new approach not only helps target treatments more appropriately, but reduces the likelihood of debilitating side effects, as the more intensive treatments can be reserved for the most aggressive tumours. Personalised diagnosis and medicine is at the very forefront of cancer treatment globally. The AIM BRAIN project will ensure access to personalised treatments for all children who need them in Australia and New Zealand, and is an exciting collaboration with the DKFZ MNP2.0 study and the Australian and New Zealand Children's Haematology/Oncology Group (ANZCHOG), our experts in paediatric brain tumours.

Earlier this year, well known Australian TV

presenter Carrie Bickmore of Carrie's Beanies 4 Brain Cancer Foundation, provided a AUD 535,000 grant to fund years three and four of our AIM BRAIN project commitment. This is incredible news, meaning we can now focus our efforts on what we feel is 'phase 2' of AIM BRAIN, helping increase the availability and quality of clinical trials for Australian children. It's also an example of how charities can work together to make change happen faster. The initiative is also co-funded by the Australian Federal Government.

### Other collaborations

Recently we've joined the Collaborative Brain Tumour Tissue Consortium (CBTTC) which provides free and open access data to assist research. CERN - the Collaborative Ependymoma Research Network - remains an important partner too. In 2017 we announced the recipient of our \$120,000 CERN Fellowship – Dr. Claire King, Research Associate at the Cancer Research UK (CRUK) Cambridge Institute. Fusion driven ependymoma is the most aggressive form of cancer with ten-year survival rates being less than 50%. Great progress has already been made by Dr. King, under the leadership of neuro-oncologist Richard Gilbertson, M.D.

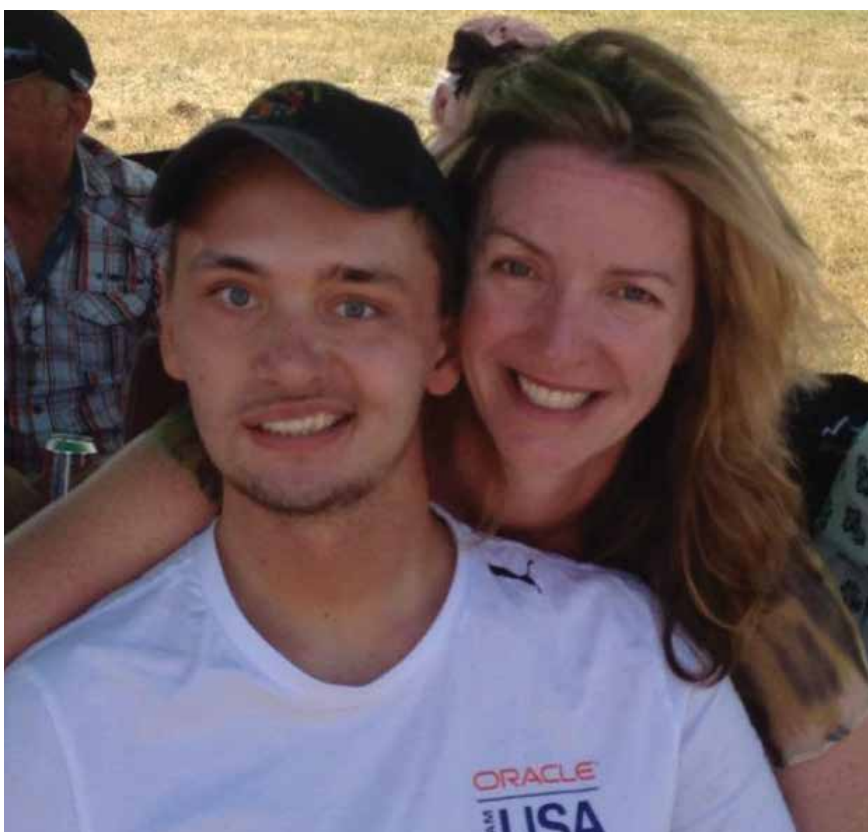
In February this year we sponsored an international ependymoma scientific meeting for fifty of the world's leading brain cancer researchers. The meeting was hosted by Dr. Mark Gilbert at the National Institutes of Health (NIH) in Washington, DC. We had hopes of hosting a cocktail event at the Australian Embassy but unfortunately mother nature had other ideas. The hotel provided a good back up venue.

### Events at the Robert Connor Dawes Foundation

Connor's Run is at the very heart of our charity. What started in 2013 as a fun run with 1,000 of Connor's family, friends, people from his school and the local community to celebrate a run he did only once (he hated running but was motivated to do so in order to train for the upcoming rowing season) has become Australia's (and I actually think the world's...let me know if I'm wrong!) largest, single event for paediatric brain cancer. In 2018, our 6th Connor's Run, we again sold out with over 4500 participants and 500 volunteers and we raised a staggering AUD 1 million. ➤



Connor's passion was rowing



Connor and his mother, Liz Dawes



The support from the community, our sponsors, our corporate teams remains incredible. Our focus is to keep the 'more fun than run' vibe. If we can do that and raise a million dollars each year for paediatric brain cancer, then it is a win-win!

In February this year we held our largest US event, Connor's Erg (<https://www.classy.org/campaign/connors-erg-challenge-2019/c209840>). Five of the top rowing universities in the US competed in a 100km virtual erg rowing challenge (an "erg" is an "ergometer" which measures the amount of work performed on an indoor rowing machine). The fourth annual Connor's Erg was the biggest yet – raising over USD 70,000 for brain matters. Northwestern Mutual Life (NML) came on as a major sponsor of the event, generously providing a \$25,000 grant to Dr Michelle Monje at Stanford. The grant was jointly given by the Robert Connor Dawes Foundation and Alex's Lemonade Stand Foundation (a large children's cancer charity in the US). The funds raised from Connor's Erg at each university will benefit the respective universities' neuroscience departments, with the remaining money raised benefiting the RCD Foundation's U.S. brain cancer research projects.



Connor (centre) with his sister Hannah and brother Nick

### Our future

Five years on we have a much clearer vision and perspective on what needs to be done in the world of paediatric brain cancer. Collaboration is instrumental in every aspect. Brain cancer is obviously tremendously complicated. There are now 140 known subtypes of brain cancer. This disease won't be cured by one person, or

one lab, or one country. We are committed to funding research that is collaborative, between researchers, institutions, countries and funding bodies.

Inspired by Connor, our biggest heart and brain, we continue onward. By positively engaging our community we hope to continue to raise much needed funds and awareness and help accelerate real progress. ■

## Walking around the world for Anna Banana

### Geri Shaffer

Executive Director, Southeastern Brain Tumor Foundation

TWENTY-two-year-old brain tumor survivor, Anna Mott from Marietta, Georgia in the United States, kicked off International Brain Tumor Awareness Week for us by "Walking Around The World" in her neighborhood. Through Facebook posts, Anna encouraged friends and family to join her as she spreads awareness about a disease which took her sight six years ago. Although her days as a ballerina are behind her, she's still able to have a positive impact on others. She is no longer dancing, but walking with a purpose and walking for a purpose.

Friends who participated in support of "Anna Banana" calculated steps taken with various apps. Collectively, the 15 participants



logged an incredible 1,177,288 steps between October 20-28, 2018! These individuals collectively walked a total of 588.64 miles - the length of the state of Georgia (the SBTf's home state) and half-way down the state of Florida. Outstanding! Great job Anna Banana, you're an inspiration to so many! ■

**Editor's note:**  
Anna Mott graced the cover of the IBTA's 2016/2017 edition of Brain Tumour magazine and inspired people around the world with

her charm, determination and courage. We were thrilled to hear about the Walk Around the World for Anna Banana and congratulate Anna, her family and friends on this wonderful endeavour!





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**Funding research**  
on brainstem  
gliomas



**Supporting  
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New clinical trial with autologous dendritic cells pulsed with tumoral cell-lines lysate  
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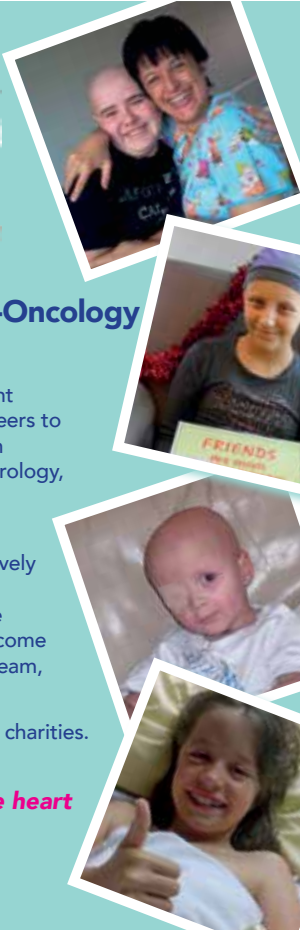
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# Getting the maximum out of patient reported data in clinical trials: an update on the SISAQOL initiative

*“Setting International Standards in Analysing Patient-Reported Outcomes and Quality Of Life Endpoints Data” (SISAQOL)*

Lien Dorme

Quality of Life Methodologist, European Organisation for Research and Treatment of Cancer (EORTC),  
Quality of Life Department, Belgium

Kathy Oliver

Chair, International Brain Tumour Alliance, United Kingdom  
on behalf of the SISAQOL Consortium



Attendees at the SISAQOL Consortium meeting held in Brussels in September 2018

The Setting International Standards in Analysing Patient-Reported Outcomes and Quality of Life Endpoints Data (SISAQOL) project can make a real difference in the lives of cancer patients.

As cancer treatment often comes along with side effects and other physical and emotional consequences, patients and their families are not only concerned about the cancer cure, but also about how they will feel during and after their treatment.

Patient reported outcomes (or “PROs”) provide information about the impact of disease and treatment on the quality of life and symptoms from the patients’ perspective. There has been an increased interest from researchers to collect these PROs in cancer clinical trials when evaluating new cancer therapies. To gain information on a patient’s

quality of life with a certain treatment, researchers collect forms and questionnaires, through which patients report how they are feeling and/or functioning.

A lot of effort goes into the collection of PROs, both from the hospital team and from the patient. Patients devote their own time to completing quality of life questionnaires, often while not feeling well. However, despite all these efforts, there is no general consensus on how these data should best be analysed and how the research results should be reported. The lack of standards and clear guidelines in PRO research has led to the situation where a large variety of statistical methods are being used to evaluate the data from these questionnaires, and often these methods are not suitable for these ➤

complex questionnaire data. This heterogeneity in the analysis and in the reporting of PROs makes it very hard to synthesize evidence from different clinical trials.

Although PRO research has sufficiently guided decision-making for several decades now, there is still room for improvement in the standardization of PRO analysis and reporting. This is exactly why the SISAQOL Consortium was established: to set international standards and recommendations on how to analyse PROs and health-related quality of life data in cancer clinical trials.

### SISAQOL benefits

When selecting the most appropriate treatment, patients want to make an informed decision and want to know what lies ahead of them in all possible scenarios. A comprehensive understanding of the benefits and the risks of the cancer treatment is key for an informed decision making.

Additionally, for approval or non-approval of a new cancer therapy at the regulatory level, it is very important that the process of decision-making is well informed, so that the right cancer treatments are approved. The development of better standards in PRO methodology will lead to more robust PRO data, leading to more meaningful benefit-risk decision making when reviewing the results of individual trials, as well as easier and more accurate comparisons across clinical trials.

### Making better sense of the numbers

There are many possible statistical methods to answer a certain research question and there is no such thing as a 'golden' standard technique for analysing PRO data. It can, however, be a real challenge to become familiar with all of the different analysis methods that are currently being used. Imagine if we were able to cut down this number of analysis techniques to just a few appropriate analysis methods. All efforts could then be focused on a few techniques. This can help clinicians and patients make better sense of the numbers, hopefully fostering communication of the obtained research evidence between patients, caregivers, researchers and other stakeholders. Also, this could allow researchers to be more efficient when analysing data, which may result in faster release of research results.

### Strong international partnership

The SISAQOL initiative is strongly committed to its goal to create international standards for analysing PROs in cancer clinical trials. However, for these guidelines to be accepted and broadly used, it is very important that the different needs and requirements from all the different stakeholders are taken into account. This is exactly where the power of SISAQOL lies: in its strong international and multidisciplinary partnership. The SISAQOL Consortium is an expert group, consisting of quality of life researchers, statisticians, a patient organization and stakeholders worldwide, voluntarily collaborating with the shared objective of working together to improve patient-centred care.

### Three priorities

From the start of the SISAQOL initiative in 2016, this Consortium of experts has met regularly to pursue their goal through discussion in repeated face-to-face and virtual meetings. In January 2017, the

Consortium met to discuss relevant issues and set three key priorities for the coming years. These priorities are based on limitations in the current PRO research practice in different cancer fields.

**The first SISAQOL priority** concerns the reporting and formulating of a research hypothesis. There are many possible ways to support the efficacy of a new cancer treatment. One could, for example, be interested in the proportion of patients that experienced a clinically meaningful worsening during the entire treatment period, but one could also be interested in a patient's average health related quality of life after the first cycle of chemotherapy. These research questions may yield correct, but opposite conclusions about the same treatment, although arising from the same data. These simply answer different research questions and require a different method of analysis. Currently, PRO research questions tend to be broad and uninformative for statistical analysis. As such, it is very important that a clear and detailed research hypothesis is specified before the clinical trial starts. That is why SISAQOL aims to formulate a set of well-defined research objectives and provide guidelines for their use.

**The second SISAQOL priority** is to select statistical methods appropriate for analysing PRO data and to match these with the research objectives. In order to make this process as objective as possible, the selection is based on a set of essential statistical criteria that a method should fulfil. This way, new statistical methods can, in the future, be subjected to the test and added to the list of PRO-appropriate analysis techniques.

**The third and final SISAQOL priority** focusses on using a good strategy for handling missing PRO questionnaires, which is nearly as important as the choice of an analysis method. Thus, the third key SISAQOL objective for improving the current PRO research practice is to also recommend appropriate strategies for dealing with missing data.

### An update

Building on two years' work in each of these three prioritized fields, the SISAQOL Consortium came together in September 2018 to approve a set of concrete guidelines for the analysis of patient reported outcomes in cancer clinical trials. This was a necessary last step before writing and making publically available these academic SISAQOL guidelines.

As a next step, after the guidelines are published, we plan to create SISAQOL publications in lay language, so that patients and patient advocates can become more familiar with the project and can engage in spreading SISAQOL's important messages. In the near future, we also hope to pursue stronger collaboration with more patient advocacy groups around the world, fostering better ties and communication between the patient and all other stakeholders. Through improving research, enabling more informed decision-making and better communication between parties, we firmly believe that SISAQOL has the power to ultimately lead to better patient-centred care in the cancer field. With PRO data that are exploited to the full and with statistical analyses done in the most careful way, we could get the most possible out of PRO data. Efforts from patients and clinicians to collect PRO data would be more valuable than ever. ■

**Members of the SISAQOL Consortium are:**

**Ethan Basch** (Lineberger Comprehensive Cancer Center, University of North Carolina, USA); **Andrew Bottomley** (European Organisation for Research and Treatment of Cancer – EORTC, Belgium); **Melanie Calvert** (Centre for Patient Reported Outcomes Research, University of Birmingham, UK); **Alicyn Campbell** (Genentech, USA); **Charles Cleeland** (Department of Symptom Research, University of Texas MD Anderson Cancer Center, USA); **Kim Cocks** (Adelphi Values, UK); **Corneel Coens** (European Organisation for Research and Treatment of Cancer – EORTC, Belgium); **Laurence Collette** (European Organisation for Research and Treatment of Cancer – EORTC, Belgium); **David Collingridge** (The Lancet Oncology, UK); **Nancy Devlin** (University of Melbourne, Australia); **Lien Dome** (European Organisation for Research and Treatment of Cancer – EORTC); **Amylou Dueck** (Alliance Statistics and Data Center, Mayo Clinic, USA); **Hans-Henning Flechtner** (Clinic for Child and Adolescent Psychiatry and Psychotherapy, Universität Magdeburg, Germany); **Carolyn Gotay** (School of Population and Public Health, University of British Columbia, Canada); **Ingolf Griebisch** (Boehringer Ingelheim International GmbH, Germany); **Mogens Groenvold** (Department of Public Health, Bispebjerg Hospital and University of Copenhagen, Denmark); **Laura Lee Johnson** (Office of Hematology and Oncology Products, Center for Drug Evaluation and Research, US Food and Drug Administration – FDA, USA); **Madeleine King** (School of Psychology and Sydney Medical School, University of Sydney, Australia); **Paul Kluetz** (Office of Hematology and Oncology Products, Center for Drug Evaluation and Research, US Food and Drug Administration – FDA, USA); **Michael Koller** (Center for Clinical Studies, University Hospital Regensburg, Germany); **Daniel C Malone** (College of Pharmacy, University of Arizona, USA); **Francesca Martinelli** (European Organisation for Research and Treatment of

Cancer – EORTC, Belgium); **Sandra A Mitchell** (Outcomes Research Branch, Healthcare Delivery Research Program, Division of Cancer Control and Population Sciences, National Cancer Institute – NCI, USA); **Jammbe Z Musoro** (European Organisation for Research and Treatment of Cancer – EORTC, Belgium); **Daniel O'Connor** (Medicines and Healthcare products Regulatory Agency – MHRA, UK); **Kathy Oliver** (International Brain Tumour Alliance – IBTA, UK); **Madeline Pe** (European Organisation for Research and Treatment of Cancer – EORTC, Belgium); **Elisabeth Piault-Louis** (Genentech, USA); **Martine Piccart** (Institut Jules Bordet, Université Libre de Bruxelles, Belgium); **Chantal Quinten** (European Centre for Disease Prevention and Control – ECDC, Surveillance and Response Support Unit, Epidemiological Methods Section, Sweden); **Jaap C Reijneveld** (VU University Medical Center, Department of Neurology & Brain Tumor Center, The Netherlands); **Christoph Schürmann** (Institute for Quality and Efficiency in Health Care – IQWiG, Germany); **Jeff Sloan** (Alliance Statistics and Data Center, Mayo Clinic, USA); **Ashley Wilder Smith** (Outcomes Research Branch, Healthcare Delivery Research Program, Division of Cancer Control and Population Sciences, National Cancer Institute – NCI, USA); **Kathy Soltys** (Health Canada, Canada); **Rajeshwari Sridhara** (Office of Hematology and Oncology Products, Center for Drug Evaluation and Research, US Food and Drug Administration – FDA, USA); **Martin Taphoorn** (Leiden University Medical Center/Medical Center Haaglanden, The Netherlands) and **Galina Velikova** (Leeds Institute of Cancer and Pathology, University of Leeds, St James's Hospital, UK)

**NOTE:** The views here reflect that of the individual authors and should not be construed to represent official views or policies of the US Food and Drug Administration, US National Cancer Institute, Medicines and Healthcare products Regulatory Agency, Institute for Quality and Efficiency in Health Care, Germany or Health Canada.



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The American Brain Tumor Association is a trusted resource for brain tumor **patients, caregivers and health care professionals** around the world. From a wide range of publications to webinars and educational programs, the ABTA provides information on all tumor types, for all age groups and empowers patients and families by helping them better understand the diagnosis.

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# ARTC

**Brain Tumors Research Association**

## To support neuro-oncological research

The Association's main goals are to improve basic, translational, and clinical research in the field of brain tumors and to support hospital services.

## To act specifically

The ARTC deals mainly with primary brain tumors. Research laboratories and clinical Departments are supported directly and through fellowship grants. A particular attention is paid to research on quality of life issues. Moreover, ARTC recently developed a program to support neurooncology training and care in French-speaking Western Africa.

**a.r.t.c@free.fr**

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Groupe Hospitalier Pitié Salpêtrière  
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WHO SUFFER FROM BRAIN  
TUMOR AND THEIR FAMILIES**

### OUR ACTIVITIES

**Consultations and solutions for patients' problems and worries with the cooperation of medical experts. Collection and distribution of latest information to patients and their families (gatherings and internet). Events to exchange experience among patients and their families.**

**http://jbta.org**

## OUR OBJECTIVES

Improve Medical Care System for Rare Cancer Patients.

Develop Better Treatments (surgery, drug therapy, radiation therapy, immunotherapy, nuclear medicine, etc.)

Accelerate Basic Research, Translational Research, and Clinical Trials to Find a Cure.

Provide Rare Cancer Information and Share Information  
Create a society more adapted to rare cancer patients and their caregivers and provide them a high quality of life.



**Rare Cancers  
J A P A N**

**rarecancersjapan.org/en/**  
contact: info@rarecancersjapan.org

### OUR NETWORK IN JAPAN

Cure Sarcoma  
DIPG Symposium Organizing Committee  
Ewing Sarcoma Patient Family Group  
Family support group for Retinoblastoma (Sukusuku)  
GISTERS  
Japan Association Mesothelioma and Asbestos Related Disease  
Victims and their Families  
Japan Brain Tumor Alliance (JBTA)  
Japan Sarcoma Patients Network "TANPOPO"  
Lisianthus support group for Children Diseases  
Melanoma Patients Association - Over The Rainbow  
Neuro-Endocrine Tumor Patients Association (PanCAN Japan)  
Pediatric Brain Tumor Network of Japan (PBTN)  
PMP patients' Network of Japan  
Rare Cancer Patients' Network  
Rhabdomyosarcoma Family Network  
Thymoma and Thymus Cancer Patients' Association "Futatsuba"

# Inaugural World Children's Hospice Forum Yokohama, Japan

## Hisato Tagawa

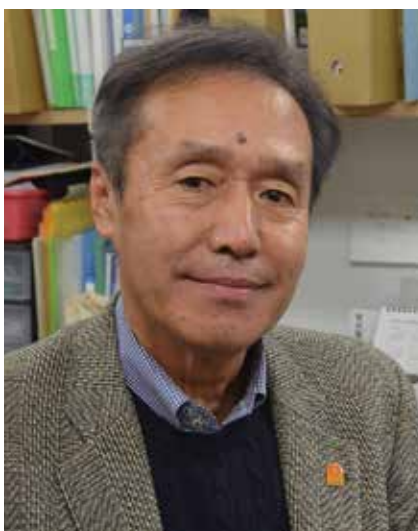
Director of Yokohama Children's Hospice Project (Japan)

In Japan, there are approximately 20,000 children living with life-limiting and incurable conditions, such as paediatric cancers or genetic and neurological diseases. Japan is a country known for its advanced medical technologies and precision instruments. But despite the medical advances, palliative care and the support system for these children and their families have not kept pace and still leave much to be desired compared to European countries.

When my second daughter was diagnosed with a malignant brain tumour in 1997, what we felt during the five months from diagnosis to the end of her life was not only gratitude toward the medical services but also frustrations. What we needed was not just medical care, but also time together as a family. We also felt increasingly isolated from society, and the empathetic words from some of the medical staff were our only consolation. That experience later drove me to setting up a non-profit organization to provide support for sick children and their families.

In 2013, we received a bequest from a former nurse, Ms Ishikawa, who had a dream of opening a children's hospice in Japan. Such a facility, based on the British model of children's hospice, and now spreading worldwide, was (and still is) virtually non-existent in Japan. With a conviction for the need of such a facility, we immediately started fundraising for the construction cost. The goal is to raise 360 million yen and we have now reached 300 million yen.

At the end of September 2018, we visited children's hospices in Germany, The Netherlands and the United Kingdom to learn more about children's palliative care. What we found was an amazing support system for socially vulnerable people which was included as part of national healthcare policies. Upon our return to Japan, we



Hisato Tagawa

organized the First World Children's Hospice Forum in Yokohama, on February 11th, 2019, inviting representatives from those children's hospices, the Chief Executive of the International Children's Palliative Care Network (ICPCN), and our partners in Japan

who are working to establish children's hospices and improve children's palliative care here in our country.

### The aim of the Forum was to:

- (1) learn from countries with advanced experience in this area,
- (2) provide an opportunity for different countries to exchange ideas and experiences,
- (3) obtain ideas on how Japan can develop children's hospice and children's palliative care that are adapted to Japanese culture, institutional systems etc., and
- (4) raise awareness and promote children's palliative care in Japan, so all children and families living with life-limiting conditions can receive the necessary care and support and have enhanced quality of life.

Part 1 of the Forum consisted of country presentations about the history and the ➤



One of the sessions at the World Children's Hospice Forum in Yokohama

operation of children's hospices. The six speakers were (1) Reverend David Ireland, Chief Executive Officer, Francis House, UK; (2) Gillian Bevin, Director of Care, Francis House, UK; (3) Wilma Stoelinga, Director, Kinderhospice Binnenveld, the Netherlands; (4) Ilse Vasterman, fundraising professional, Kinderhospice Binnenveld, The Netherlands; (5) Makoto Nabetani, Superintendent, Yodogawa Christian Hospital, Japan; and (6) Julia Downing, Chief Executive, International Children's Palliative Care Network.

In Part 2, children's hospice care and questions from the audience were discussed in the form of a symposium. Professor Takaaki Yanagisawa, Department of Neurosurgery, Jikei University School of Medicine, moderated the panel, which consisted of the above six speakers and Ms Shihoko Kikuchi (a Japanese mother of a child with cerebral palsy, who had used a children's hospice in Germany). I was also on the panel.

Listening to the discussions about the country differences in terms of how children's hospices began and how systems were

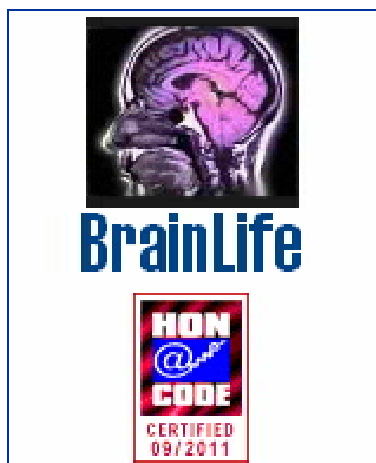


Speakers and delegates at the first World Children's Hospice Forum in Yokohama, Japan

established, we discovered that despite the differences, we all share the same values. In order to promote children's palliative care in Japan, we confirmed the desire and the need to continue providing care with the same warmth and empathy, with respect for the children and their families, with an eye to address the local needs, never forgetting the passion to continue. We felt the need for a change of atmosphere in Japan, where

the family is expected to be the sole carer for children with diseases. We also felt the need for increased support for the siblings of these children.

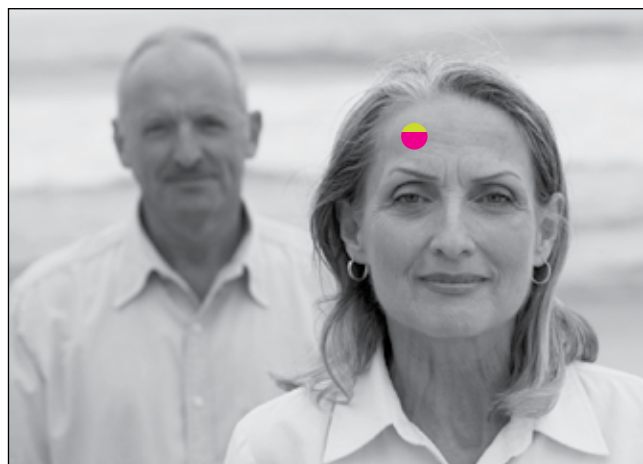
The Forum enabled us to deepen our friendships with each other and develop a greater sense of community. We closed the day with hope for future development in Japan and the global growth of children's hospice care services. ■



**[www.BrainLife.org](http://www.BrainLife.org)** collects and offers for free to patients, caregivers and medical/health professionals, a database of the latest published research on brain tumors. From peer-reviewed medical journals, abstracts and full-text articles are collected with their original contents.

New entries are highlighted in issues of the electronic newsletter **Current Neuro-Oncology**.

The web site is monitored by an international **Scientific Advisory Board** and certified by the **Health On the Net Foundation**.



## The Norwegian Brain Tumour Association

The Association was established in 2009 and is an independent, national organisation for people who have or have had brain tumours, their families and other interested parties.

Please see [www.hjernesvulst.no](http://www.hjernesvulst.no)

If you are interested to sign in as a member or learn more about us, please contact us at [post@hjernesvulst.no](mailto:post@hjernesvulst.no)



Hjernesvulstforeningen



# How a nurse navigator can help on the brain tumour journey

Sherry Fox, PhD, RN, CNRN, FAAN

Expert Nurse Navigator/Advocate, Virginia, United States

*Working as a neuroscience nurse for over 40 years, Dr Sherry Fox has cared for people with stroke, brain tumors, brain injury and many other neurologic disorders including hydrocephalus. Sherry currently uses her extensive experience and passion to navigate clients to their best quality of life and state of health in an innovative nurse navigation organisation called Ask Nurse Debbie.*

Health care, both in hospital and outpatients, is becoming more and more complex and chaotic by the day. As health care entities become more pressured to produce profit, quality can be compromised as patients are pushed faster and faster through the system. Add to the complexity of the health care system a complicated, frightening disease like a brain tumor and the challenges grow exponentially.

Nurses, particularly those with long time experience, are uniquely skilled in navigation and advocacy for patients. These professionals often possess an “insider” knowledge that few have within the health care system. An experienced nurse navigator can speed up processes, reduce frustration and smooth the path as you try to obtain the care you need.

You may ask what specifically can a nurse navigator do to help a brain tumor patient? A nurse navigator can assist with many issues the person with a brain tumor will face over the course of their illness.

## Navigating through the health care system

First, the navigator can give you a broad overview of your disease and how it might progress thus helping you anticipate what resources you will need. This is called “anticipatory guidance”. Many patients turn to the Internet for this type of education. While you may glean some useful information there, the information is often cursory and not always accurate. Many may look to their physician for information, but physicians often do not have the time to help you see a long view of what is happening nor the pragmatic information to deal with signs and symptoms that you will face. Nurse navigators have the knowledge for which you are looking.



Dr Sherry Fox, nurse navigator

Next, a nurse navigator can locate and put in place resources to address your health care needs as assessed above. Having a navigator can save you time in locating those resources when you are already ill and stressed.

Finding clinical trials and experts for second opinions is particularly important when living with a brain tumor. Nurse navigators can locate these resources with speed and they can often open doors that a non-medical person or individual patient cannot. Nurse navigators can also assist with resources that supports daily living such as finding meal preparation services, transportation to appointments, in-home help, legal services, medication management, and paperwork management to name a few.

Having a brain tumor comes with many ups and downs in the course of the illness. These ups and downs are often unpredictable. A nurse navigator will have a sense of the ups and downs from previous experience and can monitor your progress

and communicate with you about that. This type of knowledge is called “tacit” knowledge. While you can call your physician’s office for this guidance, you may often encounter individuals who, while helpful, don’t really understand the “ups and downs” and often cannot respond in a timely manner.

## Living day-to-day with a brain tumor

Immediacy and accessibility are often important when living with a brain tumor. For example, the fear of having a seizure and managing when it happens or preventing it from happening come along with day-to-day living. Also, changes in personality and feelings are common and confusing. A nurse navigator can often be immediately available to answer questions and address your concerns as opposed to waiting for return calls from your busy health care practice.

Frequent communication is important when living with a brain tumor, particularly one which is high grade, and questions can arise almost every day. A nurse navigator can implement a plan to visit you, call you and communicate with your family if you desire. More importantly, a navigator can be the “go between” with the health care team. It is often difficult to communicate your questions and desires in the complex health care world. A skilled nurse navigator can help you define your questions, communicate your desires and most importantly get answers to your most pressing questions in the hospital, in your physician’s office and when you are at home.

Unfortunately, the journey of having a highly malignant brain tumor will often shorten life. There is no more difficult challenge than making the decision to fight for cure or to seek quality of life and ➤

comfort care. An experienced nurse navigator can spend time with you working through those decisions. The skilled navigator would help you ask critical questions such as how long a treatment will help you survive and what cost you will incur (both financially and mentally) to seek that cure. Similarly, the experienced nurse navigator may be able to suggest alternative/complementary treatments and interventions that you may discuss with your physician and that will enhance quality of life during treatment.

If your brain tumor journey results in a shortened life, the experienced nurse navigator can assist you and your family in understanding the dying process. Dying from a brain tumor is often not like dying of other illnesses or cancer. There are unique signs and symptoms that are associated with the dying process of a brain tumor patient with which the typical hospice nurse or physician is not familiar due to the rarity of a brain tumor diagnosis. Having an experienced nurse navigator with you and your family can make dying easier, if there is such a thing.

In closing you might be asking how to find an experienced nurse navigator? There



Dr Sherry Fox, nurse navigator, with a former caregiver whose husband passed away from a glioblastoma.

are several possible sources to locate a navigator. First, ask within the health care system you are using for your treatment if there is a nurse navigator who might assist you in your journey. In some countries, the services are typically covered under your treatment and/or insurance for that facility. Ask specifically if there is someone with experience in working with brain tumor patients. If you are unable to locate a navigator within your country's health care

system, look to national organizations which support people with brain tumors to see if they can help with finding a nurse navigator.

Finally, while a relatively new health care concept, there are nurse navigation services available for a fee which you may choose to engage on a limited or long-term basis to help guide you in your brain tumor journey. ■

For further information, contact Dr Sherry Fox via [www.asknursedebbie.com](http://www.asknursedebbie.com)

National Brain Tumor Society

## Conquering and curing brain tumors - once and for all

We are pleased to stand beside our friends at IBTA in the fight against brain tumors.

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A CURE FOR  
BRAIN  
TUMOURS

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Low-grade brain tumours can lie undetected for many years before symptoms suddenly appear and turn victims' lives upside down.

They cause progressive mental and physical problems, and sometimes transform to a more malignant form of brain tumour.

Astro Brain Tumour Fund is working hard to end the anguish for those living with this devastating form of cancer by funding research in the UK and providing a Facebook support group for patients and carers.

For more details, please contact

Mary on **01485 52 52 79**  
[treasurer@astrofund.org.uk](mailto:treasurer@astrofund.org.uk)

Linda on **02084 05 88 53**  
[lindatruster@astrofund.org.uk](mailto:lindatruster@astrofund.org.uk)

or browse our website at [www.astrofund.org.uk](http://www.astrofund.org.uk)

# Every Support Group Needs a Sam

Joyce Powell,  
Epidermoid Brain Tumor Society (EBTS)  
Administrator and Retired Board Member

TOGETHER WE THRIVE...  
**EPIDERM****OID**  
BRAIN TUMOR SOCIETY

*In a children's book called Green Eggs and Ham, written by the renowned Dr Seuss, there is an unforgettable character called "Sam-I-Am". Sam-I-Am is very much like a curious kid, always up to something and with an energetic spirit, he is always asking questions and wanting answers. Sam-I-Am never gives up and gets the job done.*

*The Epidermoid Brain Tumor Society in the United States knows a lad who is very much in the same mould as Sam-I-Am!*

*Meet Sam Kieffer, age ten, of Pittsburgh, Pennsylvania in the United States. Sam, like Sam-I-Am, is busy too and spreads his energy around town. He's an entrepreneurial guy and the greatest salesman. He is the boss of his team which is composed of his younger brother, sister, cousins, and close friends, and he creates busy work for everyone. What is Sam's work? It's not selling green eggs and ham! No. His main job is running a traveling lemonade/treat stand that benefits the Epidermoid Brain Tumor Society (EBTS), an on-line international brain tumor organization.*

*Here is Sam's story...*



Meet the Kieffer family of Pittsburgh, Pennsylvania, USA. Left to right: Jesse (age 6), Dad Kenny, Savannah (age 4), Mom Terri and Sam (age 10)



In 2016, Terri Kieffer from Pennsylvania, USA joined the Epidermoid Brain Tumor Society (EBTS) to gain support and information for her husband, Kenny, who was diagnosed with a rare epidermoid brain tumor in 2012. Kenny Kieffer has had surgery twice for the epidermoid brain tumor.

The Kieffer family has an older son named Sam, now aged ten. Sam is a regular boy with a caring heart. He enjoys video games, comics, books, traveling, politics, history, math, rock music, cooking, and all things 1980s. Sam also lives by Gandhi's words, "You must be the change you want to see in the world."

At the time of his Dad's second epidermoid brain tumor surgery, Sam was only seven. Being wise beyond his years, Sam realized then that the epidermoid brain tumor, being recurrent, would grow back after resection. He was told that there was barely any research for epidermoid brain tumors, and there are no treatments other than undergoing multiple brain surgeries.

Sam wanted to do something about this. Knowing that his dad and other patients supported by the EBTS organization needed research, Sam - with help from his mother, Terri - wrote a letter asking for people's help. He also set up a gofundme page in the US. Sam's gofundme page became very successful in securing donations for EBTS and motivated EBTS members along with family, friends, and community neighbors to donate for epidermoid brain tumor research.

Although this gave much satisfaction to Sam, he didn't stop there and has enlisted a team composed of his brother Jesse (six), sister Savannah (four), cousin Emma (eleven), Emma's twin brothers (eight) and close friends Quinn (eleven) and Maeve (eight), who have embarked on a new way of soliciting funds for epidermoid research by setting up a traveling roadside lemonade and treat stand at various events. At one event, a traveling motorcycle group stopped and assisted Sam and his team with volunteer help and donations.

Since launching his gofundme campaign and traveling lemonade and treat stand, Sam and his team have raised over US \$12,000 for epidermoid brain tumor research.

EBTS members are amazed and grateful to Sam and his family, friends and community. ■



Sam and his trusty team. Left to right: cousin Emma, Sam, friend Quinn at the back with cousin Jamey, sister Savannah and brother Jesse



Sam and his younger brother, Jesse, selling lemonade, rocking and entertaining customers

"Hello everyone!

I'm Samuel Kieffer and I am the head of Save The Brains. Now, I started out not knowing what was going on with my dad, but I was informed he had a rare brain tumor. I was also told there was no cure. I wanted to help!

I started organizing fundraisers. Thus, began the greatest journey ever, the journey to Hogwarts. Just kidding!! Sorry but I had to add some humor. Anyway, thus began Sam's Save The Brains!!! I started with a small gofundme page, then I passed my fundraising goal and moved on to bigger and better things like a lemonade stand.

When business started booming, I thought we needed to go further than just a lemonade stand. I decided to add baked goods. Business was really BOOMING!!!! And then one day, I was watching the news and they were showing Pittsburgh. I thought, oh my gosh, what if I set up my lemonade stand somewhere else? When I told my parents, they thought it was an awesome idea. That is how my traveling lemonade stand began.

We now do seasonal stands with baked goods. This winter was the first hot cocoa stand and it was very successful. It is very important to me that all products at our stands are homemade and the best we can make. Generous donations mean so much that I want to return the gesture with quality beverages and treats. I always sneak a couple of treats for myself but please don't tell my mom - shhhh!!!

So now you know why and how I started SSTB (Sam's Save The Brains).

I hope that my team grows larger and we find a cure for epidermoid brain tumors. No more injustice of having a brain tumor with no cure!

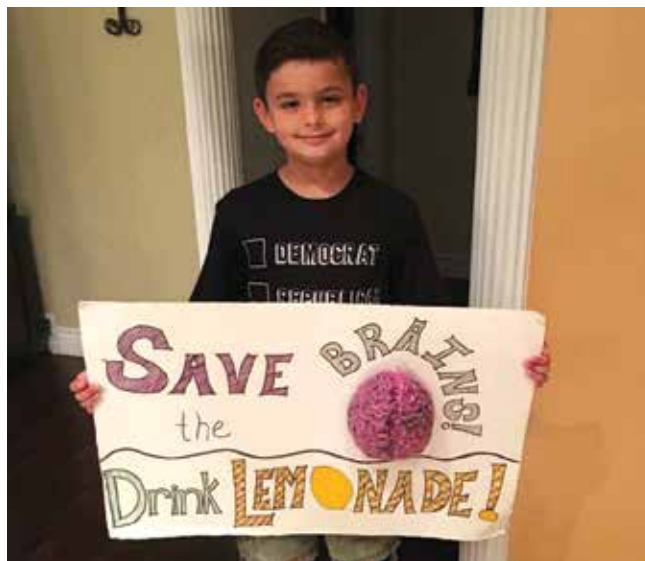
Thanks to everyone for your love, care, and support!

**Samuel Kieffer**, age ten

The Save The Brains campaign is a fundraiser webpage that benefits the Epidermoid Brain Tumor Society (EBTS). It was formed by then seven-year-old Samuel Kieffer to raise funds for research and create awareness for the rare epidermoid brain tumor.



Hope is stronger than fear – Sam's team unite for progress




Sam and one of his posters

The mission of the Epidermoid Brain Tumor Society (EBTS) is to inform, educate, support and fund research for those affected by an epidermoid brain tumor. EBTS also promotes awareness and advocates for research into epidermoid brain tumors.

Patient founded, EBTS is an incorporated, non-profit organization in the United States. It was founded in 2012. The Society has grown and now has over 1,000 members from all over the world.

For further information on the Epidermoid Brain Tumor Society (EBTS), please visit <http://epidermoidbraintumorsociety.org/>

## The Danish Association for brain tumor patients and relatives



hjerneturmorforenigen.dk

**HJERNETUMORFÖRENINGEN**

We seek to

- provide patients and their relatives with a supportive network and information
- share valuable experience between healthcare workers and patients
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Bringing together a community of brain tumour patients, caregivers and medical professionals. BTSS is working to:

- Achieve recognition of the specific challenges brain tumour patients and their carers face
- Help reintegrate survivors back into work and education
- Establish real investment in neuropsychologists and more effective long-term treatment for patients.
- Legislate for mandatory data collection in both public and private hospitals in Singapore of both malignant and non-malignant brain tumours.

[www.braintumoursociety.org.sg](http://www.braintumoursociety.org.sg)  
[enquiry@braintumoursociety.org.sg](mailto:enquiry@braintumoursociety.org.sg)



# ERN-EURACAN: The European Reference Network for Rare Adult Solid Cancers - State of the Art

Muriel Rogasik

Network Manager, EURACAN, Centre Léon Bérard, Lyon, France

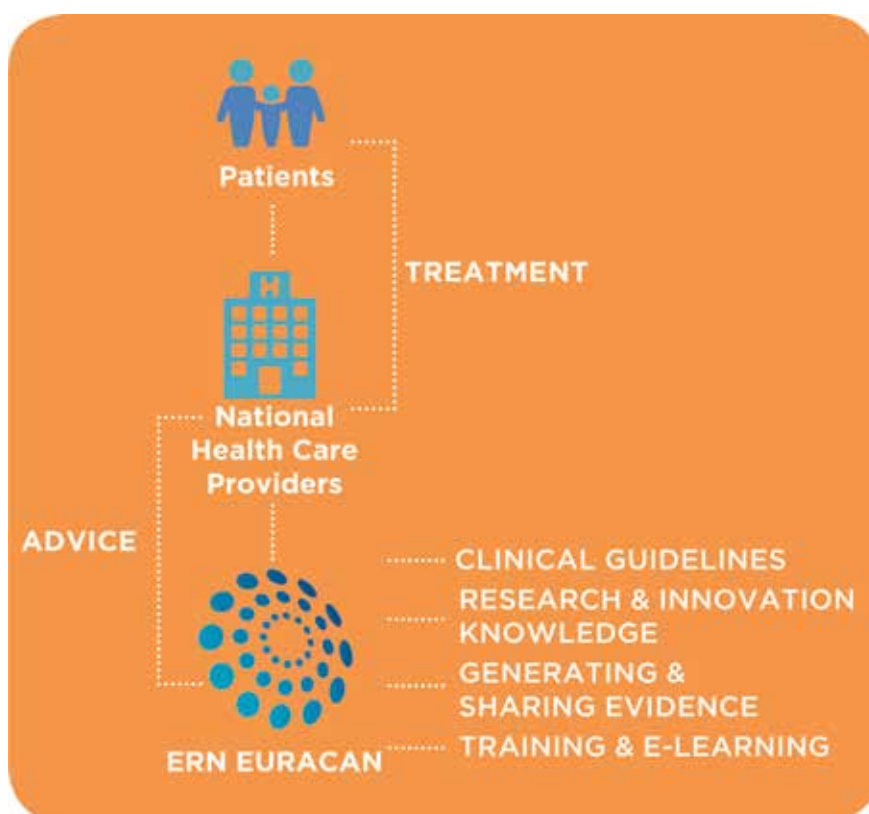


The **European Reference Networks (ERNs)** on rare diseases were launched in March 2017 and involve more than nine hundred highly-specialized healthcare units from over three hundred hospitals in twenty-six European Union (EU) countries. There are twenty-four ERNs working on a range of thematic issues including bone disorders, childhood cancer and immunodeficiency.

EURACAN is the specific European Reference Network for rare adult solid cancers and is dedicated to the improvement of diagnosis, treatment management, knowledge, research and communication about these diseases.

The EURACAN ERN is divided into ten subgroups called “domains” corresponding to the RARECARE list of rare cancers based on the International Classification of Diseases for Oncology (ICD-O): sarcoma, gynaecological cancers, urological cancers, neuroendocrine cancers, digestive cancers, endocrine cancers, head and neck cancers, thoracic cancers, skin cancers and ocular melanoma, and brain and central nervous system tumours.

Within EURACAN there are sixty-six institutions from seventeen European countries plus thirteen patient advocacy organisations working at the European level. EURACAN is coordinated by the French



Comprehensive Cancer Centre Léon Bérard in Lyon, France.

Domain 10 of EURACAN, focusing on brain and CNS tumours, is headed up by neuro-oncologist Dr Ahmed Idbaih at Les Hôpitaux Universitaires Pitié Salpêtrière in Paris, France.

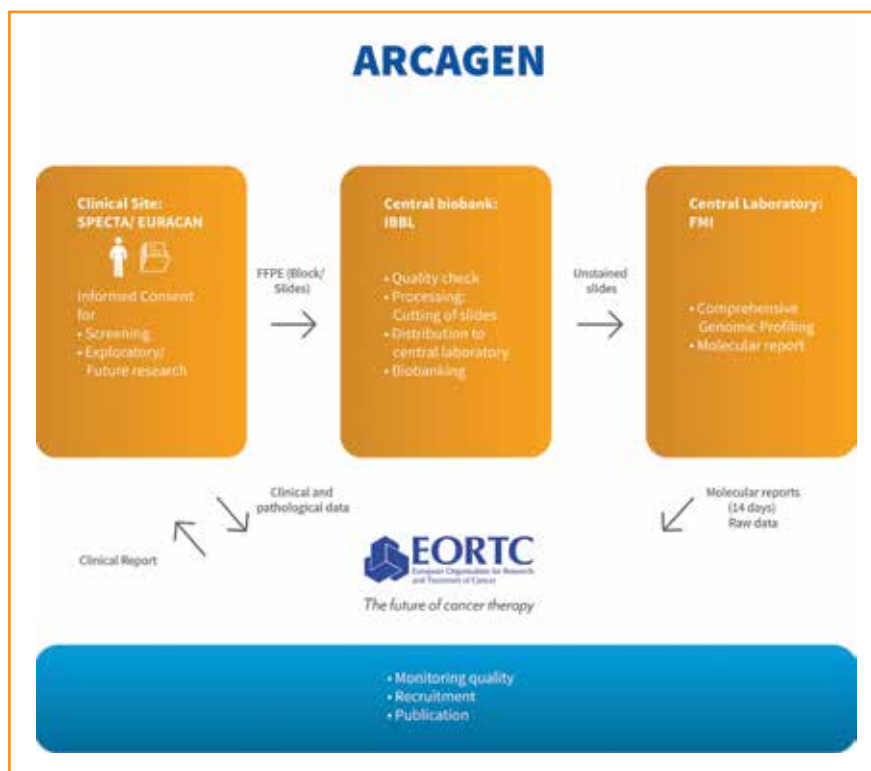
## Best Practice

The EURACAN Domains support Clinical Practice Guidelines (CPGs) to spread and align best practices. Three sarcoma guidelines have been updated in collaboration with the European Society for Medical Oncology (ESMO) and published in Annals of Oncology as ESMO-EURACAN guidelines on (1) gastrointestinal stromal tumours, (2) soft tissue and visceral sarcomas and (3) bone sarcomas.

Agreements between EURACAN and other scientific societies, such as the European Association of Neuro-Oncology (EANO - who are partners of the ERN), are on-going regarding updating and endorsing existing guidelines and duplicating what has been done with sarcomas.

EURACAN is also involved in training and educational activities. So far, these have been organized within the Domains of sarcoma and head and neck cancers in association with other EUROPEAN organizations already active and acknowledged in the field. This activity was undertaken by the EURACAN Transversal Task Force on Training and Education Activities, led jointly by ESO and the Istituto Tumori Milano in Italy.





collaboration with EURACAN, is developing a new SPECTA project. SPECTA is the acronym for **S**creening **P**atients for **E**fficient **C**linical **T**rial **A**ccess (<http://www.eortc.org/specta/specta/>). SPECTA will reach patients currently outside of clinical trials and establish a quality assured platform for collecting pathologically annotated biological material from cancer patients. The new SPECTA project is called ARCAGEN and it will involve molecular analyses of tumour tissue from patients with rare cancers using Roche's Foundation Medicine's tests. Nine hundred adult patients with rare cancers will be included in this program.

The goal of this project is to have a better understanding of the genomic landscape of rare cancers and potentially to help define possibilities for targeted treatments/clinical trials for this patient population.

The platform will support bio-specimen-based translational research and biomarker discovery and ultimately propose new therapeutic options for rare cancer patients.

SPECTA will benefit from the EORTC's expertise in translational research and its research network.

### Invitation process for additional healthcare providers to join existing European Reference Networks

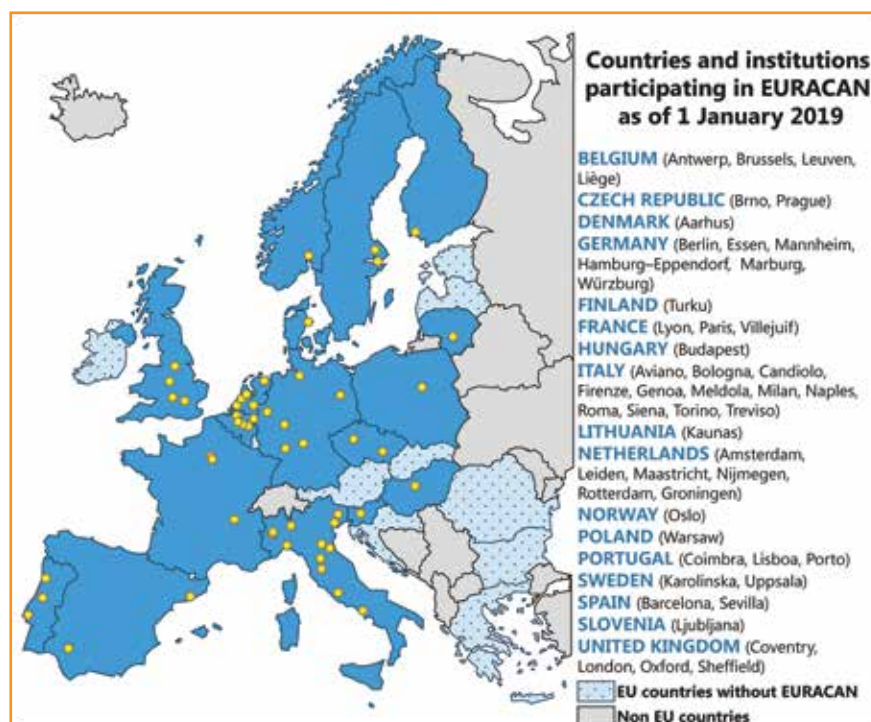
The next call for additional healthcare providers/centres of expertise to join EURACAN, and for existing centres to expand to other rare domains, will be published in May 2019.

Each candidate centre will have to provide an endorsement letter from their respective EU Member State and complete and submit files to describe their activities and expertise.

The ERNs will then give their opinion on the candidate. The final decision will then be made by the Board of Member States (BOMS) whose main tasks within the ERN system are:

- to approve Network proposals and healthcare providers' membership applications
- to approve healthcare providers wishing to join an existing Network
- to terminate a Network (evaluation) if necessary
- to decide on loss of membership

A selection process of Affiliated Centres by the Member States was also ➤



### Clinical Patient Management System

Patients across the European Union, including those with brain and CNS tumours, can have access to the best expertise available in the EU on diagnosis and treatments through a web-based clinical software application provided by the European Commission: the Clinical Patient Management System (CPMS).

This platform allows healthcare providers from all over the EU to organize virtual consultations and share experience across national borders. This platform has been customized to fit the EURACAN Domains' needs.

### Research on rare adult cancers

The European Organization for Research and Treatment of Cancer, (EORTC), in



Representatives of EURACAN attend their annual meeting at Oxford University, UK in 2018

launched by the European Commission in November 2018. Currently, ERNs do not include among their members at least one healthcare provider from each EU Member State, which could thus refer patients from the Member State to the ERN: this may represent an obstacle to ERNs' accessibility.

The Board of Member States invited the EU Member States to designate, by Spring 2019, **Associated National Centres** for those ERNs where they do not have a healthcare provider established in their territory as an ERN member. National Coordination Hubs will establish a link with all Networks in which the Member State does not have a healthcare provider as a member of an ERN or as an Associated National Centre and with which the Member State wishes to establish such a link.

Updates regarding the future call for ERNs will be posted here:

[https://ec.europa.eu/health/ern\\_en](https://ec.europa.eu/health/ern_en)

and on the EURACAN website here:

<http://euracan.ern-net.eu/> ■



There are thirteen patient advocacy organisations associated with EURACAN. Their representatives are called "ePAGs" (patient advocates). Above are some of the ePAG patient advocates at the EURACAN annual meeting in Oxford, UK in 2018. Left to right: Isabelle Manneh (European Cancer Patient Coalition, ECPC), Kathy Oliver (International Brain Tumour Alliance, IBTA), Ariane Weinmann (EURORDIS, Rare Diseases Europe), Iain Galloway (Melanoma Patient Network Europe, MPNE Ocular/Rare), Teodora Kolarova (International Neuroendocrine Cancer Alliance, INCA), Catherine Bouvier (NET Patient Foundation UK) and Jo Grey (Association for Multiple Endocrine Neoplasia Disorders, AMEND)

The IBTA maintains a list of key online clinical trials portals to help patients and caregivers locate clinical trial centres and understand criteria for joining a brain tumour trial.

For more information, visit [www.theibta.org](http://www.theibta.org)



# A European consortium dedicated to rare primary brain tumors: “EURACAN Domain 10”

## Dr Ahmed Idbaih

Sorbonne Université, Institut du Cerveau et de la Moelle épinière, Hôpitaux Universitaires La Pitié Salpêtrière - Charles Foix, Service de Neurologie 2-Mazarin, Paris, France

## Dr. Enrico Franceschi

Department of Medical Oncology, AUSL /IRCCS Institute of Neurological Sciences, Bologna, Italy

Although they are the second most common cancer in children and their overall incidence is growing, most malignant primary brain tumors in adults are classified within the category of rare cancers since their incidence is lower than six per 100,000 people in the European Union (EU). Therefore, preclinical and clinical research in the field moves forward slower compared to others oncological diseases.

However, overall, rare primary brain cancer affects a great number of patients in Europe. Indeed, approximately 30,000 new patients are diagnosed each year with a rare brain cancer (incidence) and more than 150,000 people with this disease are estimated to be living (prevalence) with a primary brain tumor (Crocetti et al., 2012). More than 100 subtypes of primary brain tumors are listed by the World Health Organization (WHO) and some of them are very rare indeed with an annual incidence dramatically lower than the threshold of six per 100,000. Therefore, combining our research efforts and resources in Europe will undoubtedly support significant and faster advances particularly in the lower incidence primary brain cancers.

To this end, the European Commission (EC) has supported the creation of European Reference Networks (ERNs) dedicated to rare or complex diseases requiring high levels of expertise for diagnosis, treatment and support. In the setting of ERNs, EURACAN is the European consortium dedicated to rare adult solid cancers overall. EURACAN is headed by Professor Jean-Yves Blay (Lyon, France). Within EURACAN, 300 rare tumors are covered. They fall within ten domains: (1) sarcoma, (2) rare female



Dr Ahmed Idbaih is the clinical lead of EURACAN Domain 10 for rare brain and CNS tumors

genital organs/placenta, (3) rare endocrine system, (4) rare endocrine system, (5) rare digestive tract, (6) endocrine organs, (7) rare head and neck, (8) rare thoracic, (9) rare skin/eye melanoma and, (10) rare brain/spinal cord tumors. The main goals of EURACAN are to provide support and care, to teach and to conduct research into rare cancers across the EU.

Up to 2019, Domain 10 (for rare brain/spinal tumors) was headed by Professor Martin van den Bent from Daniel den Hoed Cancer Center and Erasmus University in The Netherlands. One of the main upcoming achievements of EURACAN Domain 10 (which includes many leading European brain tumor specialists) is the creation of a guideline for the management of a specific rare primary brain cancer in adulthood: medulloblastoma.



Dr Enrico Franceschi is leading the EURACAN medulloblastoma subdomain

Starting this year, Dr Ahmed Idbaih from the Sorbonne University and Hôpitaux Universitaires La Pitié Salpêtrière in Paris, France took over the leadership of EURACAN Domain 10 and is carrying on the same strategy: supporting care, teaching and researching rare primary brain cancers in adults.

The major goal in terms of care is to initiate and to build a web-based clinical neuro-oncology board including various experts from different EU countries to provide European patients with a second opinion related to the medical management of their disease. This will be done through the digital exchange of patients' medical records without the patient having to travel far from home. The EURACAN network has developed web-based tools allowing secured ➤



exchanges of medical records that will be launched soon.

For the teaching aspect of Domain 10's work, publishing guidelines for physicians and patients is another objective and this will be done in collaboration with the European Association of Neuro-Oncology (EANO) and patient associations in various countries including the International Brain Tumour Alliance (IBTA).

Finally, making scientific and medical progresses is pivotal. One opportunity for this arises from the molecular characterization of brain tumors that will allow identification of diagnostic, prognostic, predictive and drug-actionable biomarkers. A project to address this is currently under discussion with the European Organisation for Research and Treatment of Cancer (EORTC).

Obviously, synergistic efforts from all European experts in rare brain tumors will help make progress in these diseases which, taken all together are actually not that rare in Europe and worldwide.

One of the guidelines which is being created by EURACAN Domain 10 is for adult medulloblastoma. This guideline will help physicians across Europe and worldwide set up the best medical management programs for their medulloblastoma patients based on the data from the medical and scientific

literature. Dr Enrico Franceschi from the AUSL/IRCCS Institute of Neurological Sciences in Bologna (Italy) will lead the writing of this guideline in collaboration with Professor Peter Hau from the University of Regensburg (Germany). on behalf of the European Association of Neuro-Oncology (EANO).

Medulloblastoma is an embryonal tumor of the cerebellum and represents the most common malignant neoplasm of the central nervous system (CNS) in children. It accounts for 15% to 25% of all childhood central nervous system neoplasms and its incidence is estimated at one per 100,000 people.

The main reason for EURACAN Domain 10's commitment to medulloblastoma is the peculiarity of this entity in adults. Indeed, medulloblastoma is extremely rare in the adult population, with an incidence of less than one per million people. But it is a potentially curable brain tumor in adults and current treatments give a five-year survival rate of up to 75%.

Medulloblastoma in adults and children are not the same, presenting differences in disease biology and location as well as treatment tolerance and side effects. Thus, results from clinical trials in pediatric populations cannot be directly translated into the adult population. Only a few clinical studies have addressed therapeutic approaches in adult medulloblastoma patients and the evidence

is very limited, as is the expertise in treating this very rare adult brain tumor. Thus, EURACAN Domain 10 has chosen to take the initiative and create this new set of guidelines and also create a special focus on this tumor within Domain 10 by creating a sub-domain speciality for adult medulloblastoma.

The multidimensional management of this disease is crucial for prognosis, and needs a particular focus from many fields, such as neuroradiology, surgery, pathology, radiotherapy, oncology and neurology. Moreover, due to the long life expectancy of adults with medulloblastoma, neurocognitive and fertility issues need to be addressed with these patients.

Recent findings in molecular biology (i.e. the "hedgehog – sonic hedgehog pathway") may provide new therapeutic targets for specific agents which will be investigated in future trials and which may improve the outcome of patients with these extremely rare brain tumors.

Due to the rarity of adult medulloblastoma and the multidisciplinary approach required for it, EURACAN Domain 10 and EANO have started a collaborative effort to define guidelines and recommendations in this setting. The guideline will include accurate and current data for the optimal medical management of adult medulloblastoma patients. ■



## *Brain Tumour Society (Singapore) pairs up with Morgan Stanley volunteers for a summer walkathon*

Ms Melissa Lim, President of the Brain Tumour Society (Singapore) - BTSS – has let us know that BTSS joined Morgan Stanley volunteers and healthcare professionals from the National University Hospital and National Neuroscience Institute for a fun morning at the Morgan Stanley Annual Charity Walkathon on 12th May 2018, at Bedok Reservoir Park in Singapore. This walkathon also marked their joint support of the International Brain Tumour Alliance's Walk Around the World for Brain Tumours campaign. The 252 participants contributed a distance of 1084 km towards this effort. Mr Ronald Ong (Morgan Stanley Chairman and CEO for South-east Asia) welcomed guests with a short speech. BTSS President, Ms Melissa Lim, congratulated Morgan Stanley for making history as the first corporate partner standing alongside BTSS for the brain tumour cause. ■

# DIPG children deserve a better chance

Hans Scheurer

patient advocate and father of Bernd, The Netherlands

It was the 14th of June 2011. Bernd, a boy of eleven years old, was in the Radboud University Hospital in Nijmegen with his parents and two older brothers. Nijmegen is a small city in the eastern part of The Netherlands, with 'city rights' that go back to the time of the Roman Empire. Bernd loved the history of it. Many Roman objects were found in construction projects around the city, and he dreamed of being an archaeologist studying mystical objects from the past.

The paediatric doctor entered the room. She usually wore a friendly smile from ear to ear, but now her face expressed sadness and a bit of grief. Bernd's MRI clearly showed the typical pattern of a brainstem tumour, specifically a diffuse intrinsic pontine glioma (DIPG).

The doctor explained why DIPG is almost impossible to treat: the location in the brain regulates vital functions like the heartbeat and breathing. Chemotherapy does not work, mainly because of the blood brain barrier that protects the brain from toxic material.

Bernd immediately jumped to the conclusion: "So, I am going to die?" It was silent in the room for a few long seconds, and the temperature felt as though it had lowered to deepfreeze.

"Yes," she said. "I'm so sorry. I need to be honest with you about this. But still there is one thing we can do, and that is very targeted radiation on the exact spot where the tumour cells are, to stop them growing. We have seen this with other patients, that radiation can give you extra time, and you could even feel recovered and relatively well for a period. I will discuss this with you and your parents more in detail later today."

The doctor and her colleague stood up to go. "I'm nearby, so if you want to talk or you have questions, I'm available, I will be back when you need me." ➤



Bernd (on the far right) with his two brothers, summer 2011, on a family trip about one month after his diagnosis of a DIPG.



"The boys". Bernd (far left) and his brothers.





For as long as possible, Bernd carried on doing the best he could with his homework. Two of his favourite classes were history and ancient Greek.

She left, giving us time to let the new situation sink in. We all felt totally lost, desperate, as if we had walked through a door and had entered a dark space, and the door is gone, you can't go back. Holding your son in your arms, having no options to protect him.

A year went by and we celebrated Bernd's 12th birthday in April 2012 with pancakes and a lot of friends from his last class in primary school as well as his new classmates at high school.

Bernd wished to proceed with his life and went to the new class, part-time, attending school for the subjects of his choice: history of course, but also ancient Greek. To Bernd the language and the myths were a fascination. To show his doctor that - to put it into his words - 'he was not a moron', Bernd wrote on a piece of paper for every appointment what he had recently learned in ancient Greek.

**In a world where more and more cancers become more treatable, it is unthinkable that this childhood cancer is still left behind with a 0% chance of survival.**



Bernd was an avid reader

We once went to a Greek restaurant, and Bernd ordered a meal in his best ancient Greek. We had a good meal though.

Bernd was losing more and more of his body's functions, and by summer 2012 he was spending his days in a wheelchair with a lot of equipment. Looking for things he could still do during the day, he started to make wooden puzzles and he made up short stories full of absurdity. The tumour did not affect Bernd's special sense of humour. He made others laugh and wrote absurd quotes on Twitter. It was his way of coping with the mess he was in.

A DIPG research group in Amsterdam contacted us about the possibility of post-mortem brain donation. My wife and I were dubious, but Bernd was immediately convinced that he wanted to donate his brain to science. The idea gave him a new purpose in life, the short life that was left for him. He knew very well that he would not survive the destructive activities of 'Minister Pons of Poop Affairs' - the name he gave to his tumour - but he still could contribute to

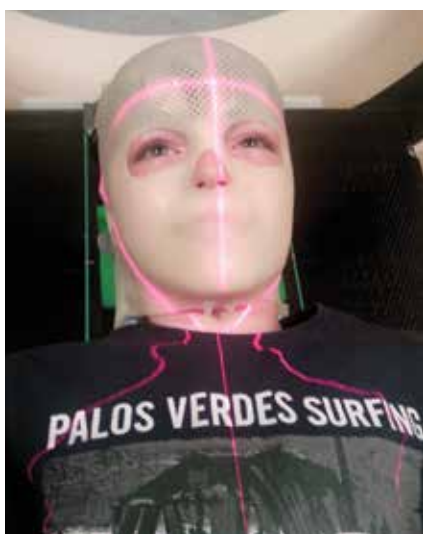
the continuing battle against the tumour by donating his brain when he was gone.

Bernd passed away on 27th November 2012.

DIPG is a very rare type of high-grade brain tumour. There is currently no cure. It is a cancer with one of the worst prognoses, leaving health professionals and family with no options but to provide palliative care.

There is a large unmet need in understanding the origin, the character, the drivers of growth of this tumour. In a world where more and more cancers become more treatable, it is unthinkable that this childhood cancer is still left behind with a 0% chance of survival.

DIPG scientists and DIPG support groups around the world joined forces and established a professional platform called the DIPG Registry - for knowledge collection, exchange and collaboration worldwide on DIPG. Historical data of DIPG cases, experimental and fundamental research publications, the



Bernd receiving radiation therapy for his DIPG tumour



Bernd with his friends at his 12th birthday party in April 2012.



**We must have more support for the DIPG community in order to improve outcomes for children with DIPG. It is unacceptable that they are left behind in research funding.**

latest information on DIPG – everything is collected on one platform for exchange worldwide, for healthcare professionals, scientists and for patients. It is a very valuable initiative.

A big problem remains the continuous funding that is desperately needed to get from fundamental research to real progress. DIPG is a very rare cancer, the patient group is small, the patients are children and have a short time to live after diagnosis, and the disease is complex in many ways. The perspectives are not yet clear enough for (market) investments, and most cancer funds prefer to fund research



By summer 2012, Bernd was in a wheelchair

projects with a clear perspective on beneficial outcomes for patients. We are not there yet with DIPG. A major effort in funding research for progress now comes

from local campaign groups and individual volunteers, often parents of a DIPG child.

We must have more support for the DIPG community in order to improve outcomes for children with DIPG. It is unacceptable that they are left behind in research funding.

You can find more information on DIPG and the local DIPG support groups in your country on the DIPG Registry at <https://dipgregistry.org> ■

**For further information, contact  
[hans.scheurer@gmail.com](mailto:hans.scheurer@gmail.com)**

**Raise awareness of the challenges of brain tumours - plan an event for International Brain Tumour Awareness Week 2019**

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## People Affected By Brain Tumours Should Never Walk Alone



**braintumour**  
*walk*



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This spring, join a Brain Tumour Walk event in Canada.

Register: [www.BrainTumourWalk.ca](http://www.BrainTumourWalk.ca)



## PHILIPPINE BRAIN TUMOR ALLIANCE

- Counselling with fellow neuro patients and family members.
- Referral of patients to neuro medical specialist (neuro-oncologists, neurologists, neurosurgeons).
- Educating fellow survivors and their families in nutrition and diet during chemotherapy, radiation and surgery.
- Encouraged better availability of clinical trials for brain tumor patients in The Philippines.
- Raising awareness of the challenges of brain tumors through public gatherings, through our provincial trip.

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## Rare Cancers:

- » More than 24% of cancers diagnosed in the EU\*
- » More than 4 million people in the EU affected\*\*
- » More than 500,000 new cases per year in the EU\*\*
- » Lower survival rates than for common cancers\*\*

Show your support and sign the  
**Call to Action Against Rare Cancers**  
at [www.rarecancerseurope.org](http://www.rarecancerseurope.org)

Rare Cancers Europe is a multi-stakeholder partnership initiative addressing methodological and regulatory barriers in rare cancer care, the need for centres of expertise and European reference networks, barriers to patients' access to care, education of healthcare professionals and access to information on rare cancers.

For more information, please visit [www.rarecancerseurope.org](http://www.rarecancerseurope.org)

\*Source: Gatta G, et al. Burden and centralised treatment in Europe of rare tumours: results of RARECAREnet-a population-based study. Lancet Oncol 2017;18:1022-39  
\*\*Source: Gatta G, et al. Rare cancers are not so rare: The rare cancer burden in Europe. Eur J Cancer. 2011 Nov;47(17):2453-61.

**R  
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Joining forces for action



# Coping with life after a brain tumour diagnosis

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Kathryn White

United Kingdom

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**EDITOR'S NOTE:** Kathryn White - formerly a clinical research scientist in the pharmaceutical industry - is based in the Chiltern Hills in England where she now runs a medical writing service, Cathean Ltd.

Kathryn's book, *Life Matters*, is an inspirational and heart-warming account of how her courage and determination - along with an unwavering love of animals - helped her to rebuild her life after the death of her husband from a brain tumour in 2008. Here, Kathryn gives a brief overview of their story, with excerpts from the book. (indicated by blue boxes). ➤



Kathryn and her beautiful horse Baz  
(photo credit: Candice Pottage Photography)



## The hell begins

It's New Year's Eve 2008 and I lay in bed unable to sleep.

*'I loathe New Year. It's a night filled with so much expectation, which it rarely lives up to in my experience. This New Year's Eve there was something else keeping me awake, something needling away at the back of my mind, in the mists of my subconscious, but I couldn't pinpoint what it was. I just had a sense of foreboding.'*

That December, my husband Ian had been struggling with tiredness and complaining he couldn't concentrate in meetings. Given our hectic lifestyle, with demanding careers and a stressful commute to work, his need to rest over the festive period wasn't surprising. Our weekends were busy too. We shared a passion for horse-riding, and loved to compete with our two horses in the thrilling sport of eventing. The exhilarating freedom of galloping across the country in the fresh air was a wonderful contrast and release from sitting in an office every day. Our pastime demanded hours of training and travelling to shows throughout the year, but we both enjoyed being outdoors and active.

February 2008 and our world was rocked to the core, when Ian's health suddenly deteriorated. It was 3:00 am and I awoke with a start. Someone was moving around the bedroom, whimpering.

*"Ian?" I called out into the darkness.  
I heard an anguished groan as I switched on the light.  
"My head really hurts," he moaned, holding his forehead with one hand, a pained expression on his face.'*

Ian was very rarely ill. In the 18 years we'd been together, he'd been sick just two days. I drove him to the local hospital where he was given a brief physical examination. Painkillers and anti-sickness tablets were dispensed before he was discharged with a diagnosis of migraine. No scans or further investigations were performed.

Over the next two weeks, the headaches became more frequent and severe. Blood tests came back negative and our family doctor prescribed ever stronger pain relief. Ian struggled to get out of bed due to his throbbing head and overpowering fatigue; when he did venture out, he found walking difficult and shuffled behind me as his guide. Something really wasn't right, so I decided to tackle our doctor myself and demand a referral to see a specialist.

I walked into the doctor's surgery.

*'I swear the receptionist could smell my fear. But, I thought of Ian lying at home, suffering. I pushed my shoulders back in defiance. I had to stand my ground and be resilient. Taking a deep breath, I fixed her with my best steely stare and repeated my request more forcefully.  
"And I'm not moving from here until you book him in," I added, managing to keep my voice from wavering.'*

Thankfully, the receptionist relented and Ian was referred to see a neurologist.



Ian jumping his beloved Moose (photo credit: Fiona Scott-Maxwell Photography)

## Finally, we get a diagnosis

*'At the allotted time, the consultant emerged from his room and I could tell from his expression as he saw Ian that he knew the cause of his problem – a look of understanding seemed to pass over his face.'*

Within an hour, brain scans had been conducted and we received the devastating news; my darling Ian had a brain tumour. A week later, he underwent surgery to extract a sample of the tumour to determine the type: a glioblastoma multiforme. We left the doctor's room that day in a daze.

*'[Ian] didn't have to say anything. The desperation in his eyes said it all. We embraced, holding each other upright, our own life support. Goodness, how I loved this special man who had been my companion, confidante and cheerleader...all my adult life.'*

A month on, my beautiful brave man died, peacefully and pain free, at the hospice where we shared his final days under the incredible care of those wonderful nurses and doctors. He was never well enough to even start any treatment.



Ian (on Moose) and Kathryn (on Willow), with Australian event rider Bill Levett (photo credit: Fiona Scott-Maxwell)



Kathryn now loves running, thanks to Mole (photo credit: Amy Whyte)

### A more spiritual life

For several months, grief and shock overwhelmed me as, suddenly, I was plunged into widowhood at 37. Then, somewhere deep inside, an over-riding desire stirred. I needed to live the life I had dreamt of as a young child, to honour Ian's life and the dreams he never got to fulfil.

And, that's what I've done.

*'That first year also taught me an important life lesson that I practise now daily. When you open your heart and mind to opportunities and are clear about what you want, the Universe delivers, albeit in its own timeframe.'*

I'm not a religious person as such; being a member of an organised religion doesn't appeal to me, though I understand why many people find this a comfort. Being spiritual and believing in a higher force, which I call the Universe, is what I feel comfortable with. Friends, my business, clients, and my animals have all come into my life as a consequence of me letting go and allowing the Universal energy to flow – not easy for a self-confessed control freak!

For example, just before I returned to work after Ian's death, a colleague emailed me to ask if I was interested in a secondment opportunity in medical writing. In my job as a clinical researcher, I already wrote some of the documents, but this role enabled me to write full time. The timing was perfect and I was accepted. Six months later, I became a permanent member of the medical writing team, which in turn led to me making the leap into self-employment a year later. Free from the shackles of a tedious commute, I made full use of the additional time and enjoyed working from home. I've met so many more of my neighbours,

got involved in volunteering within the community and enjoy the autonomy that being a business owner has provided.

### Angel whispers

*'The overwhelming love I felt from Ian, on a spiritual level, was so strong that I received what I believe to be signs from him. Some may argue they're coincidences, brought about by my desperation and grief, but, given their impeccable timing and relevance to me or my situation, I like to think they are angel whispers. And, most importantly, they provided comfort.'*

One such sign came in February 2009. The previous year, Ian was in hospital on St Valentine's Day.

"I hope you do better than this for a romantic date next year," I joked. "Oh I will," he replied with a grin.

Sadly, Ian wasn't with me in person the following year, but he kept his promise. Having lost my beloved horse, Willow, in November - six months to the exact date and time of Ian's demise - sufficient time had passed by January to consider buying another horse. Through my network, I was introduced to Wilbur, a stunning dark brown horse with a kind face and calm nature. The minute I sat on his back, I knew he was the one. And, you know what? He became mine on St Valentine's Day.

To make sure I knew Ian was responsible for Wilbur, he sent me another sign. A pair of gloves, which I had lost a few weeks before, tumbled out of a bag which I took with me on my first visit to see Wilbur. I had turned that bag inside out searching for those gloves! I've received many signs since.

*'I think my love of horses partly stems from the spiritual connection these beautiful animals seem to have – a deep wisdom and sixth sense...'*

### Animal counsellors

Through my equestrian pursuits, I have met most of my wonderful friends and secured my first professional writing projects. My equine friends are also responsible for a little terrier called Mole coming into my life, because he was bred by my riding instructor. ➤



Wilbur



He may be small in stature, but he's given my confidence an almighty boost! So many more people say hello when you walk a dog, especially one that's cute and sociable. I've joined a dog-friendly running group with whom we also enjoy paddle-boarding excursions and open-water swimming. With my canine chum beside me, I feel confident enough to go on holiday and eat out at restaurants.

*'He is my best friend and I cannot imagine life without him or another dog in the future. He brings out my fun side and I love him to pieces. Mole is a great life coach, too, because if ever you needed to see evidence of living in the moment, watch a dog. Their attention is always on whatever is going on at that point in time, whether it's chasing a ball, eating food or sniffing the hedgerows.'*

### Writing my book

Writing my book, *Life Matters*, has been a cathartic process. In it, I describe how I have rebuilt my life, and give information about the professional help and therapies I have experienced along the way. I also wanted to share our story to raise awareness of brain tumours. Symptoms may overlap with other conditions and, as Ian's case highlights, our general practitioners may not consider a brain tumour as a possible cause.

I've found that the process of grief is like peeling layers of an onion. The grief doesn't diminish; you just learn to live with it. Slowly, as time passes, you peel away layer after layer, and move forwards.

*'Life isn't easy. Change is inevitable. Challenges are par for the course. I still have my fair share of wobbly days when I want to scream and yell at the unfairness of it all; to remain within the safety of my duvet and weep. It's all part of the process of peeling another layer of that damn shallot.'*

Regardless of whether you are on a similar journey or are just looking for guidance to help you through difficult times, I hope that *Life Matters* offers support. You are not alone. ■

### EDITOR'S NOTE - *Life Matters*

Extracts from Kathryn's diary provide poignant insights into her emotional state during Ian's illness and following his death. Despite the gloom and despair, the couple still found lots to laugh about and humour punctuates the story. Kathryn shares the challenges she's faced and the therapies that have helped her move forwards. She also details how this tragedy has opened her mind to spirituality and the comfort this has brought.

*Life Matters* is available from Amazon as paperback or e-book for Kindle. A percentage of the sales will be donated to Brain Tumour Research, UK.

## The Kortney Rose Foundation - helping to get brain tumors off kids' minds

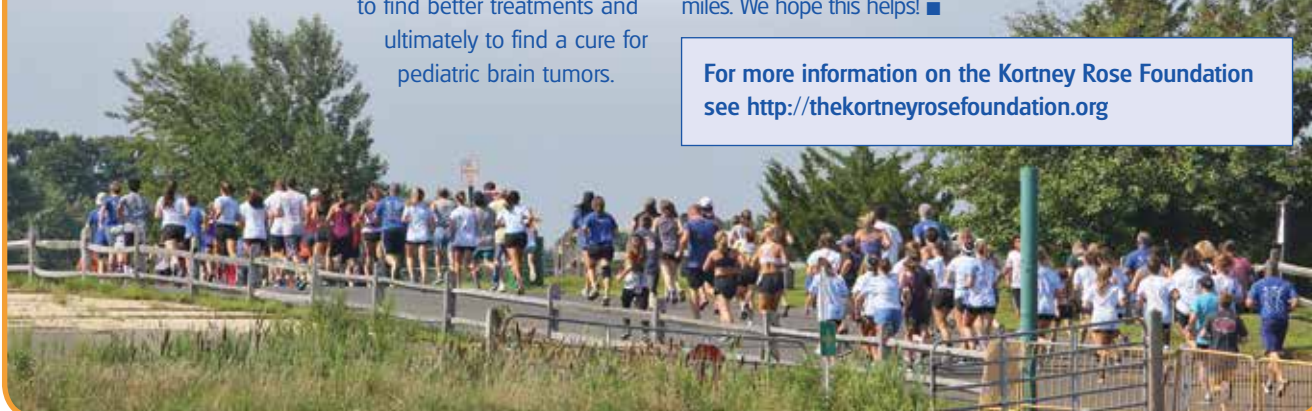
Kristen Gillette, Founder/Executive Director  
The Kortney Rose Foundation

THE Kortney Rose Foundation (KRF) is a 501(c)(3) organization that was set up by Kortney's parents as a way to help channel their grief into something positive after losing nine-year-old Kortney to a diffuse intrinsic pontine glioma (DIPG). Their hopes are to make a difference, in Kortney's name, in the fight to find better treatments and ultimately to find a cure for pediatric brain tumors.



On 5th August 2018 we held the 13th annual Kortney's Challenge Two Mile Fun Walk/Run. We are happy to announce it was a huge success with a record number of participants and dollars raised. We had about 600 registrants and raised US \$82,000 for pediatric brain tumor research. We would like to donate miles to the IBTA's annual Walk Around the World for Brain Tumors. This year we had 238 walkers at two miles each allowing us to donate 476 miles. We hope this helps! ■

For more information on the Kortney Rose Foundation see <http://thekortneyrosefoundation.org>





# Life After a Pediatric Brain Tumor

Kathy Riley, MPH, CHES

Vice President of Family Support, Pediatric Brain Tumor Foundation, Asheville, North Carolina, United States

*The Pediatric Brain Tumor Foundation has published a survivorship resource notebook to help families thrive after treatment*



A mother whose five-year-old son was diagnosed with a brain tumor more than two decades earlier described the hidden struggle of her life to a colleague.

She said: "The treatment our son received continues to have its way with him and takes a toll on him physically and cognitively. The dreams we had stored up in our hearts for our son have been re-written and re-imagined so many times that I've lost count."

## Survivorship – a new chapter in the journey

When treatment for a pediatric brain tumor ends, a new stage of the journey begins, one that can stretch on for many years like this mother's. Survivors of childhood brain tumors often deal with late effects of their treatment. The severity of those late effects depends on age at diagnosis, type of tumor, type of treatment received, and other factors. These late effects may include intellectual, physical and social impairments, changes in physical appearance, social isolation, and the psychological and emotional effects that come with diagnosis and treatment. The families of survivors suffer too, and every member is changed by the experience.

To help survivors and the people who care for them understand how to manage the complex challenges that accompany surviving a childhood brain tumor, the Pediatric Brain Tumor Foundation (PBTf), based in the United States, worked with a team of authors – parents and survivors



Kathy Riley of the Pediatric Brain Tumor Foundation in the United States

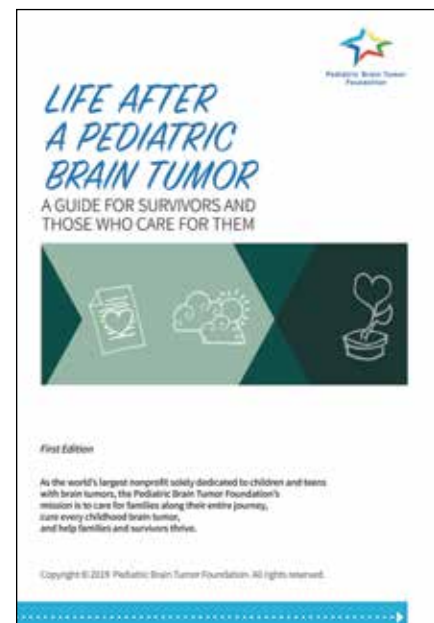
themselves, doctors, psychologists, nurse practitioners, social workers – to create a comprehensive survivorship notebook comprised of information, encouragement and advice, and forms to help survivors keep themselves, their families, and their records organized.

## The PBTf Survivorship Notebook

The process of developing this resource notebook began on a September morning in 2017, when a half-dozen survivors of childhood brain tumors gathered to brainstorm about a resource that would address the challenges they faced in the years following completion of treatment. They talked about how the physical and emotional impact of treatment shaped their outlook and how isolated they felt and still often feel. They asked questions they wished they'd known to ask back when they finished treatment: What kind of follow-up care did they need? What late effects might they experience? How independently could they live? How could they keep their

medical insurance as they aged? What kind of help was available finding a job? One survivor quieted the room when he said, "And after the threat to life is gone, the emotional pieces have to be dealt with."

During that same year, a group of parents of brain tumor survivors convened to imagine a slightly different resource, the one they wished they'd been given when their child had completed treatment. These parents had similar questions: How can my child access quality healthcare as they age? What happens to their insurance coverage when I retire? How do I empower my child to be as independent as possible? One parent wondered aloud, "What do we know about our kids? What does my child want? What do they dream?" She suggested creating a legacy document that survivors could use to record things they might want others to know about them. Other parents hoped for content addressing their feelings of grief over dreams lost and ➤



The cover of the PBTf survivorship notebook

redefined, grief over the burdens their other children must carry.

Over the course of several meetings, caregivers and survivors synthesized their questions into four general topics:

- 1) **Physical and Mental Health**
- 2) **Quality of Life**
- 3) **Working the System**
- 4) **What Has Helped**

The PBTF recruited 40 experts in the fields of pediatric oncology, education, and disability rights, along with expert parents and survivors, to write content for the notebook. A health literacy writer reshaped the material for appropriate reading level and consistent tone and voice.

### **Same journey...different perspectives**

Designed to help families navigate their way through survivorship, many sections of the notebook address both survivors and caregivers. Other sections begin with the words “Survivor perspective” and speak directly to survivors. Other sections start with the words “Caregiver perspective” and speak directly to caregivers. The notebook includes information about how to stay healthy both physically and mentally, and it provides information about how to speak up about the help survivors need. Weighing in at over 180 pages, the notebook is not meant to be read cover to cover in one sitting. Survivors and caregivers should read information as they need it to manage their survivorship challenges.

Living as a brain tumor survivor is complicated, with a host of doctors’ appointments and scans, phone calls to insurance companies, and meetings at school to get needed help. Consequently, the notebook is designed to help survivors and their families:

- 1) **keep track of important information from appointments, scans, phone calls and meetings,**
- 2) **communicate information to doctors and to write and store notes,**
- 3) **look up answers to questions as they arise, and**
- 4) **make the resource their own as they work their way into the future of their own survivorship.**

Survivors also will find templates (forms they can copy and fill out) for keeping track of the treatment they received for their



The PBTF provides support programs, including family camps, for pediatric brain tumor survivors and their families, some of whom are pictured above

brain tumor. They'll find other templates for tracking follow-up care. Information can be updated when it changes and maintained in the notebook so that survivors and families know where to find it when they need it.

As time passes, many questions arise for survivors and those who care for them. The notebook provides specific guidance about how best to take these questions to their healthcare team and others until they get the answers they need. Families can come back to the notebook with their new questions,

confident that they'll likely find the answer.

The mother who described the physical and cognitive toll her son's brain tumor treatment continues to take was one of the contributors to the PBTF's new survivorship notebook. Along with the wisdom and expertise of many other authors, it contains hers. She writes, "Survivorship is a story about running an endurance race where the finish line is ambiguous. Or maybe the finish line has been there all along, it's just not the one I wanted to cross. This is not

the path I would have chosen for my son. That doesn't mean it can't be good as we walk together."

The hope of the PBTF is that this new survivorship notebook will help survivors and those who care for them thrive as we make that long walk together. ■

For further information, please visit <http://www.curethekids.org/>

## Kicking off brain tumour awareness in Cameroon, Central Africa

Jasino Tabali Ngong, BScN, MPH-Epidemiology

Public Health Nurse and Patient Advocate, Jacob's Hope Foundation, Douala, Cameroon, Central Africa

Sport - especially football - is a wonderful catalyst that brings together different people who enjoy the great game particularly in Cameroon, Africa and the world at large.

A football match was played between Victory Veteran Football Club of Bonaberi and the SHESA-90 team (the visiting team) in Douala Bonaberi, Cameroon, Africa on 31st December 2018. Jacobs Hope Foundation for Brain Tumours and other Cancers (JHF) used this football match to raise awareness among footballers and spectators about brain tumours. The game ended with Victory Club winning by four goals to two for SHESA-90.

Players on both teams were parents with small and large households who have either been affected directly or indirectly by brain tumours or other cancers. After the game, material about these diseases was shared. This material included tee-shirts received from various brain tumour charities in other countries who have been supporting us with help from the International Brain Tumour Alliance (IBTA). These tee-shirts were distributed to the players of both clubs and also the spectators. The tee-shirts carried messages like "Saving Children's Lives" and "Be Brain Tumour Aware." The representatives of Jacob's Hope Foundation shared their caregiver and patient advocacy experiences



Raising awareness of brain tumours in Cameroon with a football match

and also talked about other aspects of the brain tumour journey, that is: its epidemiology; the situation in Cameroon; paediatric and adult symptoms; the importance of early diagnosis; the need for a second opinion; the importance of the family in the care process; different treatment centers and treatment options and where patients can get care in Cameroon, neighbouring Nigeria, Ghana, South Africa, India, Europe and America.

A small reception took place after the match where we networked, had discussions and answered people's questions about brain tumours.

This has been a great experience, encouraging us to organise another grand sporting event again (the date is still to be confirmed). The target population at the next

event will be women and girls. This group was targeted because, from our observations in the treatment centers in Cameroon, the majority of patients are accompanied to hospitals by women and the majority of caregivers of cancer patients are women. Their better understanding of brain tumours would be advantageous regarding early diagnosis and even improved health care.

We thank the International Brain Tumour Alliance, the Society for Neuro-Oncology Sub-Saharan Africa (SNOSSA), the brain tumour charities who donated tee-shirts to us and the other brain tumour charities which we met through the International Brain Tumour Alliance for letting us join the movement and impact the world of neuro-oncology in our own modest but sincere way. ■





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# End of life care but not end of life

Sacha Langton-Gilks

Dorset, United Kingdom

*Sacha Langton-Gilks is a singing teacher, garden consultant, writer and child health campaigner. Her book, **Follow the Child**, is based on her own family's experiences and those of other parents facing the death of a child from illness or a life-limiting condition.*

*Nothing in life is to be feared, it is only to be understood.*

*Now is the time to understand more, so that we may fear less.*

*Marie Skłodowska Curie*

It is now six and a half years or 2,361 days since my eldest child David, or DD as we call him, died of his medulloblastoma aged 16. His deathday fell between the Olympics and Para Olympics of London in 2012 and my memory still struggles to own the date.

Looking back, having moved beyond the worst years of grief, my overriding impression is of how lucky we were in our experience as a family of DD's end of life care.

I cannot put words to the value I attach to DD being able to tell me, before his dementia overwhelmed him, that he had no regrets at the end of his life – he had done and said everything he needed to – and I hope to be able to say the same myself when my time comes. People think I'm crazy using the word luck in the context of my child's death but they have not met the many, many families I have through campaigning.

It was lucky that we lived in an area of the UK where the greatest proportion of children and young people with cancer die out of hospital; lucky that our GP (general practitioner – our local primary care in the UK) had specific end of life care training (Gold Standards Framework); lucky our local district nurse felt confident to nurse a child at end of life; lucky that we had lived in our community nearly all of our children's lives; lucky we had family support; lucky that we had time to accept and prepare for DD's death and above all lucky that I had experienced a death before (the death my mother had managed at home for my late father). I knew death was a human event,



Sacha Langton-Gilks

not a medical one, and therefore not to be feared. It is the disease and loss that I fear.

The problem with this, and the reason why I'm campaigning so hard with many charities in the UK, is that luck, as we all know, is unreliable. We need planned systems with enough properly trained staff.

## Planning is everything

I had not processed much of this at the time. I do clearly remember how frightened I was in hospital, before DD's brain tumour was terminal, when other families 'went home'. It was literally a dead end although fear meant I would have been unable then to say the word "dead" or "die". It was that memory that led me to accept The Brain Tumour Charity's invitation, three years after DD died, to speak to other families of our experience of end

of life. I realised that someone had to speak back over that divide so that families knew what actually happens, how the support works, what choices there are – that it's not a hopeless vacuum.

The most terrifying thing is when you suspect medical professionals know stuff and they're not telling you – usually, I know now, because they fear upsetting you more or saying the wrong thing.

The core of how DD was able to live his life to the full at home those three months after his diagnosis of terminal disease, doing all the things he loved until literally the last four days of semi-coma/coma, was to do with planning.

Our main treatment centre was Southampton General Hospital and their planning centred on MDT (multi-disciplinary team) working between all the consultants and healthcare professionals involved in DD's care which included our more local hospital, Salisbury District, and our GP in our local town. We should have been connected as well to our local children's hospice for homecare and I would have got much less tired had that support been in place.

We had a 24/7 telephone number which meant that when we were at home – which was all the time, as DD never wished to be readmitted to hospital – I had instant communication to his medical team. I would never have had the confidence to stay at home without this. As long as everyone, family especially, understood what was happening, we would be prepared as well as we could be. ➤



The Langton-Gilks family (left to right): Rufus, Honey (the dog), Toby, DD, Sacha and Holly. Photo reprinted with kind permission of the Western Gazette, Somerset, England

It was the summer holidays and DD's siblings (and their friends) were nine and fourteen and they were central to DD's life continuing as normal. Their care was his care and vice versa.

Planning is, however, more complex than just the health care professionals communicating well. My obsession with it stems from three conversations.

The first was when the palliative specialist nurse said to me: "It's so much easier to do this [advance care planning/ACP] when you know what the family want." This was after I had told her that I wanted to sign a Do Not Resuscitate Order for DD and if there was any way of making sure a 999 emergency call from our house would not result in him being taken to hospital.

Second, the largest end-of-life care charity in the UK effectively saved my life during DD's last two weeks by giving us night support. But this was only possible according to them because he had turned 16 and could be counted as an adult (their remit) and "there is a good plan in place".

Lastly, I discovered that when a child is dying there is no medical scenario that cannot be dealt with at home as long as it is anticipated and planned for. I asked a paediatrician about this a few years after DD's death. Until then I had a deep-seated fear, based on understandable ignorance as a non-medic, that there might be some things so terrible that you can't manage them at home as well as unrealistic expectations fostered by the many life-saving dramas we watch on our screens.

The problem is, that as a society, we are now ignorant of the processes of a normal death and the narrative around disease is loaded with being 'brave' and 'fighting' - centred on denying that we are going to die. In the case of our children it's even harder, as parents think they are giving up on them and letting them die if they admit and accept they are going to die at some point.

You cannot plan if you cannot admit this and neither can your child. Some choices are only available with planning. In our case it was not the health care professionals who helped my husband and I understand this

but our sick child. It is why my book is called *Follow the Child*.

DD famously told a BBC interviewer on camera just after his terminal diagnosis: "I'm now kinda stuffed but hey, you can't win 'em all!" After I had reassured him that he wouldn't know when he was actually dying - after all he couldn't remember the last four times he nearly had - and the team would make sure his symptoms of sickness and pain were under control, he got on with enjoying himself. DD also wrote a will, had a huge party, went to his school prom and meditated on the teachings of Buddha if he felt stressed. Where he led, we generally all followed. His little sister once refused to let him go to bed for a rest because she wanted to play with him outside with the immortal words: "But you can rest when you're dead!" He agreed and off they went leaving me floundering speechless.

I am so grateful to my boy that his end of life care continues to comfort me to this day. It isn't an end. I know I have not had to process the added pain of regret about the manner of his death; he was calm and peaceful, just as we planned. ■





*Follow the Child: Planning and Having the Best End-of-Life Care for Your Child* by Sacha Langton-Gilks, Jessica Kingsley Publishers, 2018


THE core of *Follow the Child* stems from the speeches I have given to families and health care professionals about DD's end of life care, initially at the invitation of The Brain Tumour Charity in the UK. Families had told the charity that at the end of their child's life they had no information, no support and felt isolated.

I realised that information given within the context of family stories is very different to medical leaflets and there was nothing like this available

which focussed on the planning aspects needed for a death. So the book seeks to empower families to make the right choices for them, with practical information on how and what to plan, the choices available, what to expect before and after the death and links to useful services.

Alongside my own, the book includes the experiences of other families who made different choices, lived in different places in the UK and US, and whose children had life-shortening diseases other than cancer. The book is not about bereavement after death but does cover the bereavement experienced before death – anticipatory grief. The information in the book has been checked by nurses, social workers, palliative care consultants (in the UK and US) and Together For Short Lives, the leading palliative care charity in the UK for children and young people, as I had a terror of misinforming at such a critical time.

Writing this book made me realise how much I misunderstood generally, and also from the media or doctor's terminology particularly. There is much I wish I'd known about especially during the period between the death and the funeral and in terms of tissue donation. We just went along with what the professionals around us happened to know rather than what is actually possible. Brain donation did not exist when DD died but having read such moving testimony from a family in the US whose child had a diffuse intrinsic pontine glioma brain tumour (DIPG), I included a section on this in the book. I'm in no doubt DD would have chosen this himself had it been available, in order to contribute to the science needed for future cures. I am hugely relieved that feedback from a family who used the book in preparation for their child's death from DIPG was overwhelmingly positive. ■



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BRAIN TUMOURS ARE THE MOST COMMON FORM OF SOLID TUMOURS AMONG CHILDREN



# Using the All-Party Parliamentary Group on Brain Tumours to influence change in the United Kingdom

*The All-Party Parliamentary Group on Brain Tumours is a non-partisan group of politicians from the United Kingdom's Parliament in London. This group has helped drive transformative progress for the UK brain tumour community. Here is a review of the history of the group, how it functions and what it aims to achieve.*



All-Party Parliamentary Group on Brain Tumours meeting in April 2014 in one of the impressive rooms of the UK Parliament in London

All-Party Parliamentary Groups (APPGs) are formed of members of the UK's primary legislative chamber, the House of Commons, and members of its secondary legislative chamber, the House of Lords (both chambers act together to form the UK's Parliament). This means that APPGs are not controlled by the ruling government and ensures their direction is controlled by the membership.

APPGs are also not politically aligned. There is a rule that APPGs must contain members from at least two political parties and many of these groups go far beyond this, ensuring they have a politically diverse membership.

The Parliamentarians who comprise the membership of APPGs do so voluntarily and are not remunerated for their involvement. Many members of the All-Party Parliamentary Group on Brain Tumours (APPGBT) have joined it after hearing brain tumour stories from their constituents, others join because of a personal connection. Once a year, at an Annual General Meeting, members

of the group choose one member to serve as Chair for the year. 'Ordinary' meetings take place approximately every three months. The Brain Tumour Research charity in the UK provides the Secretariat for the APPGBT.

## Establishing the All-Party Parliamentary Group on Brain Tumours

The APPGBT was established in 2005 to raise awareness of the issues facing the UK's brain tumour community in order to improve research, diagnosis, information, support, treatment and care outcomes.

The Right Honourable John Bercow MP (currently the Speaker of the House of Commons) and Sue Farrington Smith MBE, (Chief Executive of Brain Tumour Research), were instrumental in establishing the APPGBT.

From the outset, the APPGBT was intended to provide an opportunity for everyone in the UK brain tumour sector to share news, ideas and experiences. The APPGBT's meetings, which often draw ➤



Annual general meeting in July 2018 for the All-Party Parliamentary Group on Brain Tumours

audiences of nearly 100 people, are attended by patients, their families, clinicians, academics, researchers, civil servants, charities, members of local government and representatives of industry.

### The APPGBT and raising awareness

The APPGBT was formed to help position brain tumours high on the UK's political agenda. Before John Bercow MP's involvement and the formation of the APPGBT, there had only ever been one Parliamentary Question about brain tumours. A Parliamentary Question is a question put formally to a government minister about a matter they are responsible for by an MP or a member of the House of Lords. John Bercow MP had called the first-ever debate in the House of Commons in April 2004.

In its early years, the APPGBT's focus was on raising awareness amongst key decision makers. The APPGBT campaigned on a number of critical issues such as early diagnosis, access to new treatments and increased funding for research into brain tumours.

At the end of the APPGBT's first decade, these efforts began to pay off. A 2015/2016 public petition that garnered over 120,000 signatures forced the UK government to turn its attention to brain tumours. With the support of the House of Commons' Petitions Committee, a Parliamentary debate was held in April 2016. This was attended by more than 70 Parliamentarians, who convinced a government Minister that more should be done to support the cause of brain tumour patients and their families. A Task & Finish Working Group was then established. This Group reported back in February 2018 with a series of conclusions.

As a result, the UK government allocated £20 million (approximately US \$25 million/€22 million), with an additional £25 million (approximately US \$31.5 million/€27.5 million) pledged by Cancer Research UK (the UK's biggest cancer charity).

This political momentum was given further impetus by the lobbying of Baroness Tessa Jowell, a member of the House of Lords who was diagnosed with a glioblastoma (GBM). Whilst still undergoing treatment, Baroness Jowell, who was known in the UK for being the driving force behind the 2012 London Olympics, gave a moving address to Parliament to call for access to adaptive clinical trials. The government responded by pledging another £20 million (approximately US \$25 million/€22 million) for research into brain tumours.

Baroness Jowell also helped connect the UK's brain tumour community to the Eliminate Cancer Initiative's Brain Cancer Mission, which was already active in both Australia and the USA.



APPGBT meeting in November 2018 at the Houses of Parliament, London, UK to discuss the final report of the brain tumour costs inquiry

### The APPGBT and government accountability

After successfully raising awareness, the APPGBT began to exercise a second function – holding the UK government to account. The APPGBT can get both senior civil servants and leading government ministers to attend its meetings, provide it with information and ensure the government is working to fulfil its commitments to the brain tumour community.

Today, the APPGBT also examines wider issues, such as the long-term impact of brain tumours on younger patients and how the UK leaving the European Union ("Brexit") could affect medical research.

### The APPGBT's Inquiry into the impacts of brain tumours

In 2018, the APPGBT's Chair, Derek Thomas MP (a member of the House of Commons) added a third facet to its work, namely undertaking its own research and recommending policy reforms. The APPGBT's first ever Inquiry, launched in February 2018, kicked off this work. The Inquiry examined the economic and social impacts of brain tumours. Its final report was published in late-November 2018 and its key findings concluded that brain tumours are one of the most expensive cancers in the UK, both for patients and society.

### Using the APPGBT to influence change

Since its foundation, the APPGBT has worked across the political spectrum in support of the UK's brain tumour researchers, clinicians and most importantly, patients. It has provided a critical forum for debate, as well as a platform for patients and their families to directly engage with Parliamentarians.

Many international legislatures have equivalent informal groups and the experience from the UK is that, given time and administrative support, such groups can become powerful advocates for a whole nation's brain tumour community. Such groups can form an influential part of the political system, providing both an opportunity to raise awareness amongst policymakers and even directly change government policy. ■

For more information on the UK All-Party Parliamentary Group on Brain Tumours, see <https://www.braintumourresearch.org/campaigning/appg-on-brain-tumours>



# Linking image-guided neurointerventions with drug delivery to the brain



Children's Brain Tumour  
Drug Delivery Consortium  
Accelerating Progress in Drug Delivery



core  
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Children with  
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Keeping families together

Emma Campbell, PhD, BSc

Consortium Project Manager, Children's Brain Tumour Drug Delivery Consortium (CBTDDC),  
Children's Brain Tumour Research Centre, University of Nottingham, United Kingdom

From 10th to 11th June 2019, in Baltimore, USA, two organisations will come together for the first time to host a joint meeting to boost research in drug delivery to the brain.

SIGN (the Society for Image-Guided Neurointerventions) and CBTDDC (the Children's Brain Tumour Drug Delivery Consortium) have organised an exciting meeting agenda covering a wide range of neurointerventional techniques. Delegates will span multiple disciplines, including chemistry, engineering, physics, medical practice and information technology. They will be able to join in discussions to identify opportunities and challenges in image-guided precision medicine for brain tumours and other neurological disorders.

## Why bring these areas together?

In the past decade or so, the brain tumour community has seen significant progress in both the discovery of new therapeutic targets and the development of novel anticancer drugs. Unfortunately, however, advances in how to deliver these drugs to the brain lag behind.

The strict "border control" of the blood-brain barrier (BBB) restricts entry into the brain of many small-molecule drugs and nearly all large molecule drugs that have been developed to treat brain disorders. In fact, it is estimated that more than 20 million patients worldwide currently suffer from disorders of the central nervous system that would benefit from better transport of drugs across the BBB!

There are other societies and organisations that run meetings discussing the latest research in various aspects of neuroimaging or in the treatment of individual brain diseases. To our knowledge, however,

none of these brings together the diverse groups of physicians, scientists, engineers, pharmacologists and industry, from different specialities, to focus on the unique aspect of image-guided neurointervention. Indeed, most strategies for drug delivery to the brain fail to incorporate neuroimaging. By combining our expertise and our specialist communities, SIGN and CBTDDC will bridge this gap during the Baltimore conference.

## What we hope to achieve

We are providing a forum that brings together neuroimaging expertise and a wide range of techniques for drug delivery to the brain. Through stimulating multidisciplinary discussions around the opportunities and challenges of our shared goal - to improve the precision and efficacy of drug delivery to the brain - we hope to open up avenues for more synergy between the neuroimaging and drug delivery fields. This will pave the way for accelerated progress in the treatment of brain tumours and other neurological disorders. ■

## Background to the organising bodies

### The Children's Brain Tumour Drug Delivery Consortium (CBTDDC - [www.cbtdc.org](http://www.cbtdc.org);

@cbtdc) launched in March 2017. Core funded by the charity Children with Cancer UK, this initiative aims to:

- raise awareness of the challenge of drug delivery in childhood brain tumours and other brain diseases; and
- initiate and strengthen research collaborations to accelerate the development and translation of drug delivery systems that target brain diseases.

### The Society for Image-Guided

Neurointerventions (SIGN - [neurosignsociety.org](http://neurosignsociety.org)) launched in 2018 as a result of growing technological capacity within several different fields, including interventional neuroradiology, MRI, PET, neuropharmacology and artificial intelligence. SIGN's mission is to foster therapies for brain and spinal cord disorders while preventing toxicity to the rest of the body through advancing methods for image-guided neurointerventions.



Invited speakers from all over the world at the first SIGN conference in Warsaw, Poland

# Reflections on ASNO 2018 in Beijing

Chris Tse

IBTA Senior Advisor, New Zealand

*The 15th Meeting of the Asian Society for Neuro-Oncology (ASNO 2018) was held in Beijing, China, from 25-28 October 2018. The IBTA was represented at this conference by Chris Tse (New Zealand).*

Stepping off the plane into the vast expanse of Beijing's new airport, I was immediately taken aback by the sheer size of the terminal building. The inter-terminal train ride to the baggage area seemed more like a morning commute to work. Although this was my fourth visit to Beijing, it was the first since my wife, a long term survivor of a glioblastoma, was diagnosed in 2006. I was interested to learn about the state of brain tumour treatment in China, and to reacquaint myself with the city I had last visited thirteen years ago.

Each year, the Asian Society for Neuro-Oncology (ASNO) holds its annual scientific meeting, showcasing the best and most promising brain tumour research from the Asian region. ASNO was established in 2002 by the five national neuro-oncology societies of Japan, Korea, China, Taiwan and Turkey. They have since been joined by national societies from India, Australia, Hong Kong, Indonesia and the Philippines, to form the current ten-member countries of ASNO. China has hosted the ASNO meeting twice previously but this was the first time it was held in the nation's capital, Beijing.

In his welcoming address, ASNO Executive President Professor Guihuai Wang (Tsinghua University, Beijing) quoted the famous Chinese philosopher Confucius: "How happy we are, to have friends from afar", setting the scene for a welcoming and collaborative meeting.

## Presentations at ASNO

The keynote speech was delivered by Professor Mark Gilbert (USA), Chief of the Neuro-Oncology Branch of the National Cancer Institute (NCI). Dr Gilbert presented an excellent update on immunotherapy approaches in the treatment of brain



Professor Guihuai Wang delivers the opening address at ASNO 2018 in Beijing, China

tumours, with a particular emphasis on clinical trial design. He highlighted the various challenges that immunotherapy trials present, including: overcoming immunologically "cold" tumours; pseudoprogression; the effects of corticosteroid use; and treatment induced lymphopenia. He stressed the importance of designing multi-faceted clinical trials with correlative biology and outcomes assessments to better understand immune effects and predictive markers.

Clinical research was also the focus of Dr Motoo Nagane (Japan) who gave an overview of brain tumour clinical trials recently undertaken by the Japan Clinical Oncology Group (JCOG) Brain Tumor Study Group. He provided detailed summaries of seven of the Group's clinical trials, including ongoing phase 3 trials in anaplastic glioma, high-risk diffuse astrocytoma, recurrent glioblastoma and primary central nervous system lymphoma.

Dr Nagane's presentation was followed by Dr Yong-Kil Hong (Korea) whose presentation was titled: "The Hope of Repurposing Drugs in Glioblastoma: Chloroquine, Levetiracetam, Metformin". This was one of a number of presentations featuring repurposed drugs, a strategy which is proving popular in Asia as it is



Professor Mark Gilbert (USA) delivers the keynote address on immunotherapy approaches to treat brain tumours

seen as a fast and cost-effective way of achieving improved outcomes for patients. Dr Hong's group has two multicentre phase 2 trials underway featuring levetiracetam (for newly diagnosed glioblastoma) and metformin (for recurrent glioblastoma).

A highlight of the opening session was the presentation "The Role of Informal Carers in Glioma: A Qualitative Study" by Dr Zarnie Lwin (Australia). Although caregiver burden has been recognised as a significant factor in brain tumour patient care, this study exposed some lesser known challenges commonly faced by carers, including: the strain of managing hope and positivity; maintaining the ➤



Dr Zarnie Lwin (Australia) addresses the opening plenary session at ASNO 2018 and spoke about the important role informal carers play in the care of brain tumour patients

balance between optimism and realism; managing the patient's expectations; and dealing with well-meaning family and friends. It was refreshing to have a presentation highlighting the importance of psychosocial support and its impact on patient quality of life amidst a programme otherwise dominated by basic science and translational research.

### A richly diverse programme

The remainder of the programme featured oral presentations covering a diverse range of topics from neurosurgery to neuro-oncology, tumour biology and pathology. Host country China provided just over half of the conference presentations with 51%, followed by Japan (16%), Korea (10%), India (5%) and Taiwan (4%). Reflecting the geographical diversity of this ASNO meeting, there were also presenters from Australia, the Czech Republic, Egypt, Indonesia, Hong Kong, Russia, Thailand, Turkey and the United States.

Education played a prominent part in the conference programme, with separate pre-congress meetings in neuro-pathology, paediatric neurosurgery and precision and minimally-invasive spinal surgery. I sat in on a well-attended neuro-pathology meeting which highlighted updates, advances and practical implementation of the 2016 WHO classification of CNS tumours.

It is natural for each ASNO meeting to reflect the trends and influences of the host country. Alongside research topics which are being studied in other countries, this meeting featured presentations on disease areas more prevalent in China, and drug compounds perhaps not so well known in other parts of the world.

For example, traditional Chinese medicine (TCM) is still widely practiced in China, and it was evident from some of the presentations that it remains an area of interest among the country's brain tumour researchers.

The diverse nature of the conference presentations gave me a renewed sense of hope that meaningful progress could be achieved in the fight against brain tumours. That researchers from all corners of the world were attacking the problem from different directions opened the possibility that one or a combination of their approaches will eventually find a cure.



From left to right: Chris Tse (New Zealand), Professor Mou Yonggao (China), Dr Jing Wu (USA), Professor Mark Gilbert (USA), Nurse Zhang Huifang (China)

### A personal story

Prior to the conference opening session, I set out to arrange the IBTA display table. In error, my allocated exhibition space was temporarily occupied by a group of young people from the local subsidiary of a multi-national pharmaceutical company.

I told them about my wife's experience with a brain tumour and how her diagnosis had led me to be involved in patient advocacy. The group turned out to be most helpful, translating my signs into Chinese and distributing my material to conference delegates.

Later that morning one member of the group, a young man who had heard me talking about my wife's brain tumour, pulled me aside for a private chat. He told me his father had recently died of a glioblastoma. Though he didn't speak much English, with my basic Chinese and the help of the translation app on his phone, he managed to tell me his story.

The young man explained that his father was fortunate to have the connections and financial means to allow him to be treated at one of the top hospitals in Beijing. However, without extended family support, he and his mother had found the unfamiliar role of primary carers a difficult one. There were no patient organisations or support networks to help them through his father's brain tumour journey. Following his father's passing, he and his mother had been left to cope with life on their own.

I got the impression that he had not told his story often, and it was perhaps the recognition that I was a fellow brain



IBTA senior advisor Chris Tse (New Zealand) (left) and Honorary President of ASNO 2018 Professor Chen Zhongping (China)



Professor Ryo Nishikawa (Japan) addresses delegates at the opening ceremony of ASNO 2018

tumour patient carer that allowed him to speak to me so openly. There was nothing I could really do except to offer my condolences to him and his mother, but I felt privileged to be able to lend an ear to this young man. It was a timely reminder that despite the ongoing advances in research like those presented at this ASNO meeting, there was still a long way to go in terms of supportive care to improve outcomes for brain tumour patients and their families. ■



# ASNO comes to Taipei, Taiwan

*The Asian Society for Neuro-Oncology 2019 Annual Scientific Meeting will be held in Taipei, Taiwan from 26th to 29th September. The local organisers are the Taiwan Society for Neuro-Oncology (TSNO).*

Once a year, over 400 neurosurgeons, oncologists and medical researchers from the ten member countries of the Asian Society for Neuro-Oncology (ASNO) gather together with invited guests from around the globe to share their knowledge and experience, engage in spirited discussion, and enjoy the hospitality of friends. The 2019 ASNO organizing committee anticipates an outstanding conference this year, providing a great opportunity for delegates to exchange ideas freely in the meeting, learn about new breakthroughs in brain tumour treatments, meet more colleagues, build new friendships and explore the beautiful city of Taipei.

The theme of the 2019 conference is "Advances in Neuro-Oncology and Clinical

Treatments". The three-day conference program will feature presentations covering:

- brain tumour clinical research including neurosurgery, medical oncology, radiation oncology, clinical trials and pathology
- brain tumour basic research including immune-oncology, medical engineering and artificial intelligence (AI)
- nursing, paramedical care, secondary data analysis
- spinal tumours
- paediatric tumours

The organizing committee is headed by ASNO 2019 President Dr. Wei Kuo-chen and General Secretary Dr. Chen Pin-yuan,

both from Chang Gung Memorial Hospital in Taiwan. They have assembled an impressive international faculty, with guest speakers from the USA and Europe joining Asia's leading neuro-oncology specialists to present a varied and exciting program.

A great strength of ASNO is its diversity and this will be reflected in the conference delegates, expected to include leading academics, technologists, clinicians, laboratory specialists, pharmacists, patient advocates, clinical research nurses and other healthcare professionals integral to bringing new treatments from bench to bedside.

The plenary sessions will feature cutting edge developments and illustrate the variety and breadth in the field of neuro-oncology. From the submitted abstracts there ➤

**ASNO 2019**

**The 16<sup>th</sup> Meeting of the Asian Society for Neuro-Oncology**

**September 26-29, 2019**

**HNBK International Convention Center**

*Welcome to Taipei!*

Logos: ASNO, TSNO, and two QR codes.

will be nearly forty oral presentations and around eighty posters. These presentations will represent the very best in brain tumour science and will be sure to generate stimulating discussion and new collaboration throughout this conference and beyond.

Taiwan is known as the “Illa Formosa” (the “Beautiful Island”) and the 2019 host city, Taipei, is a modern, vibrant metropolis which is rated one of the most livable cities in Asia. Its mix of traditional Chinese culture, cuisine, architecture and friendly people make it one of the premier travel destinations in the region. ■

The IBTA seeks no financial contribution for a brain tumour organisation to be listed as a supporter for its major projects - we just want you *to do something* to raise awareness.

## About the International Brain Tumour Alliance (IBTA)



THE IBTA, founded in 2005, brings together experience and expertise from a wide range of stakeholders including patient organisations, researchers, healthcare professionals, government agencies, regulators, medical societies, key opinion leaders and others. Our vision is a world free from the fear of brain tumours. Our mission is to advocate for the best treatments, information, support and quality of life for brain tumour patients, offering them, their families and caregivers hope – wherever they live in the world.

We work with Alliance supporters to:

**ENCOURAGE** the establishment of brain tumour patient groups in countries where they don't yet exist;

**PROMOTE** collaboration on programmes and projects to benefit the brain tumour community;

**HIGHLIGHT** the challenges and needs of patients and caregivers;

**DISSEMINATE** knowledge, information and best practice;

**HELP** shape health and research policies at national and international levels;

**HONOUR** the courage and achievements of brain tumour survivors and caregivers.

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# Living through and learning from a brain tumour experience



**Dr Neil Bindemann**

Executive Director, Primary care and Community Neurology Society

"WOULD you mind taking a seat, the doctors are examining your scans. They'd like to come and talk to you."

Well that was it! Because I was in shock, I was wrapped in a blanket and I've never had so much sugar in a cup of tea.

I found myself in a room with three surgeons.

"We've found a mass.... you have dangerous hydrocephalus... we need to admit you to hospital, so a bed is being arranged."

There was I thinking I'd just have the tests and go home and see my local neurologist for a follow up. Because of my neuroscience background and several years running the Primary care and Community Neurology Society (P-CNS), I thought I might have multiple sclerosis. But a brain tumour had crossed my mind.

Phoning my wife to tell her "I'm not coming home" was rather tricky, to say the least. But before I got chance, she said: "Can I call you back? I'm just getting the children from school." To describe my thoughts at that point, would need a few \*\*\*\*\*!

Friday, 13th March 2015 is forever etched in my memory. The day of my operation. The operation went well; the hydrocephalus was no longer and although the surgeon couldn't remove the entire mass, he debulked it, removing sufficient for a biopsy. He also fitted something called a 'Rickham reservoir' – a dome-shaped device placed under the scalp with a plastic tube that goes into a ventricle in the brain; the purpose being to minimise any future intracranial pressure.

Fast forward one week. I had recovered from the surgery, passing the occupational therapy and physiotherapy tests, and was back home. But a big question mark hung over my future until my phone rang. It was just as we were leaving the restaurant where we had celebrated our wedding anniversary. It was my surgeon. The news was encouraging. The mass was a slow growing grade 2 pineocytoma. I needn't return for further surgery and would have an MRI scan in three months. What a relief!

## Learning point one

As I live through my brain tumour experience, my first learning point concerns the importance of preparing people for when they leave the security of the high level of care received from a specialist hospital. No matter what type of brain tumour, and in fact, whatever the diagnosis, the sense of isolation once you are back home is not insignificant. I know I'm not alone in such a feeling.

Therefore, I would suggest it would help if a staff member explained - either to a family member or patients themselves - that it's not unusual to experience feelings of isolation after a



The 'Bindepeople' on holiday on Dune du Pilat, France 2018. Left to right: Neil Bindemann, daughter Grace, wife Eleanor and son Arthur

stay in hospital, which may in part be due to patients becoming attuned to the relative safety of the hospital environment. Such an explanation may help people cope better once they are home. Plus, it offers an opportunity for patients to consider ways, prior to returning home, to help adapt. I'm sure ideas offered by the hospital staff would be welcomed!

When I got home, the impairment of my immediate recall/ short term memory became more apparent. Luckily, with my neurosciences background I rationalised that, given the need for the surgeon to tease apart regions of my brain associated with memory, the neurons would reconnect with practice and time.

I still remember that hallelujah moment when I was rewarded for such thoughts. I had been out in the garden, and I went to make a cup of coffee. But where was my mug? I'd had it in the garden. I then recalled being in the shed, of all places. And yippee, there the mug was, on the shelf! I can't tell you how much that lifted my spirits.

I had spent months since the surgery fretting about losing my house keys and my wallet. Every time I left the house, ➤



I constantly checked my pockets, rather urgently. Virtually every time visiting a shop or café or on a train to return home I asked myself: "Have I got my wallet?" Then I would urgently check my pockets, doing the same for my house keys. But I still kept practicing my immediate recall, making mental notes of actions I had taken, hoping to get those neurons rapidly reconnected! So, you see, it was a very significant moment for me, remembering that I'd left an object in a rather obscure place like the garden shed. I believe my level of mental fitness, which I now give presentations about, contributed.

### Learning point two

My second learning point is this. If it is known that neurosurgery will impair any aspect of a person's memory (even just for a short time) and consequently interfere with everyday activities (thus impairing quality of life), they and their partner and/or family need the necessary preparation and support from the healthcare services.

But perhaps my key learning point comes from the most eye opening experience, which in my opinion illustrates why we need primary and community care health services to be far more engaged in neuro-oncology care. It would require them to take such a simple step and it would make such a dramatic difference to so many patients' and families' lives, not to mention the potential cost savings from supporting and building a person's mental fitness.

A few days had gone by since returning home from hospital. I had started back to work. I held the belief (and still do), that my rehabilitation would accelerate by working. That stems, in part, from my father's attitude of what I term "living through illness", plus his exceptional psychological skills and desire to support people's quality of life. I also had a need to work, as I am self-employed.

One morning, during those early weeks, a letter arrived. When I realised it was from the hospital my heart rate suddenly accelerated. I needn't have worried. It was a copy of the discharge letter which the hospital had sent to my general practitioner (GP). I read it and didn't think any more of it.

But the discharge letter started to irk me as I continued to work through my memory deficit, the quality of life impact of my driver's licence being revoked and the accompanying loss of independence - to say nothing of my rather uncertain future. Why had nobody from the healthcare professional team been in touch? The answer to that question, which left me rather aghast, will appear in due course in an article on [www.neurodigest.co.uk](http://www.neurodigest.co.uk).

### Learning point three

So - getting to my third learning point. When a patient and their family have experienced a trauma like a brain tumour which has been clearly documented in the hospital discharge letter, please, please, please can the powers that be make sure that someone from the local general medical practice or even a developing community neurology service picks up the telephone and calls the patient and family. It doesn't have to be the GP. It could simply be the practice nurse or a caring receptionist, who calls to say something like: "Hello Mr/Mrs/Ms Xxxxx. I see you've had a rather difficult time these past few weeks, so we just wanted to give you a call and make sure you're okay. If you do need to talk then we're here to help."

If companies can set up automated telephone systems to try and trap you into enquiring about insurance scams, surely it can't be too difficult for health services to simply place a human being at the end of a telephone call!

Thankfully my mental fitness approach continues to help me through my daily life post-brain tumour diagnosis. And I believe it has contributed - along with my decision in March 2018 to go on the ketogenic diet - to the wonderful news I received this March, which was that my brain tumour has remained stable. ■

**For further information about the work of the Primary care and Community Neurology Society (P-CNS) please see <https://p-cns.org.uk/> or contact Dr Neil Bindemann at [neil.bindemann@p-cns.org.uk](mailto:neil.bindemann@p-cns.org.uk)**



The International Brain Tumour Alliance has served on the European CanCER Organisation (ECCO) Patient Advisory Committee (PAC) for a number of years and is proud to contribute to the crucial work on cancer policy in which ECCO specialises.

## European CanCER Organisation (ECCO)

THROUGH its 27 Member Societies - representing over 150,000 professionals - ECCO connects and responds to all stakeholders in the European oncology arena. ECCO exists to provide a cohesive platform for European cancer societies and organisations to work together to improve cancer patient outcomes and to be the unified voice of the European cancer professionals' community when addressing policy issues.

Through initiatives such as its Essential Requirements in Quality Cancer Care (ERQCC) - as we went to press a new ERQCC on glioma was being formulated - ECCO harnesses the expertise and experience of the European oncology community to address questions of common concern, looking collectively for answers that will result in the best possible outcome for cancer patients through informed policy-making.

ECCO invites all interested stakeholders to join the debate on European cancer policy by attending its European Cancer Summit in Brussels from 12-14 September 2019. Patient representatives can register for 75 Euros before 25 June 2019. For more information about ECCO visit [www.ecco-org.eu](http://www.ecco-org.eu) ■

# Piecing it together - sewing the way to brain tumour awareness

**Dr Anke Brüning-Richardson**

Senior Lecturer in Biomedicine and brain tumour researcher at the University of Huddersfield, United Kingdom

In the 2018/19 issue of *Brain Tumour* magazine, I produced a short article outlining the development of my public engagement activities in relation to my career in cancer research (including seven years concentrating on brain tumours).

The most recent of these has been 'Piecing It Together', the creation of a quilt dedicated to brain tumour sufferers, their relatives and brain tumour research. Aided by an appeal in the IBTA magazine, I received over 100 textile squares from Britain, Europe, Canada and the USA. The squares were made by both children and adults, by brain tumour patients and their relatives, scientists and brain tumour charities. The common purpose which connected them all was a determination to make a difference to this disease.

The squares were assembled and stitched together by textile technicians at the University of Leeds in the UK. The quilt has been exhibited at the School of Design, Clothworkers Central, University of Leeds, as part of the art exhibition *Art and Science: Another Way of Looking* which included works by myself and the artist Deborah Gardner. Having recently taken up a permanent position as Senior Lecturer in Biomedicine and brain tumour researcher at the University of Huddersfield, it is my aim to bring the exhibition to Huddersfield next.

The individual textile squares sent to me were often accompanied by messages - memories of loved ones, messages of hope and courage, and encouragement to continue with my research:

**"The maple leaf, being a Canadian symbol, inspires kind thoughts, wishes and – most of all – support from across the miles (from a cold place)."**

**"I really really appreciate and love it when someone finally does something and is not only talking about it."**

**"The ribbon is a symbol for many types of cancer, including pink for breast cancer, and I felt that the association of the ribbon and cancer is extremely strong and easily recognised."**

**"My link with brain tumour research in Leeds is pretty tenuous though I manage a small team of information specialists supporting health research. I also have a personal link since my father-in-law sadly died from a brain tumour."**

**"What a great idea."**

Reading these messages, I was reminded of the terrible impact that brain tumours have on sufferers, their families and friends, but also



Brain tumour awareness quilt producer Dr Anke Brüning-Richardson with the impressive completed creation

the great bravery, character and humour that these same people can summon up.

It is important that such reminders take place regularly. Life as a scientist can sometimes be isolating. The confines of the laboratory, the rigour of scientific procedure, the somewhat sterile language of the professional journal combine to produce a sense of abstraction, separating the researcher from those who he or she hopes will benefit from their research.

This separation is not just mental but also emotional; whilst we as scientists based in cancer research may concern ourselves with gliomas, malignancy and tumour grades, sufferers and their families will face uncertainty, fear, hope and anger, amongst many other emotions. ➤



A poster advertising the exhibition where the Piecing It Together quilt was unveiled. Pictured at left is Dr Anke Brüning-Richardson. Pictured at right is the artist Deborah Gardner who was also exhibiting her work

The production of the 'Piecing It Together' quilt has reinforced my belief in the great value of public engagement activities for both patients and researchers. It has the potential to bind these two different groups together more tightly, leading to greater understanding, whilst the creation of a piece of artwork like the quilt allows the researcher to communicate their ideas outside of the usual channels such as journals and conferences.

It also acts as a stimulant to the scientist in the laboratory, reminding them that the primary purpose of their research is to make

a positive difference to the lives of sufferers, and that no matter how frustrating a matter like, for example, a repeatedly failing experiment might be, progress will come. ■

**For further information on the "Piecing it Together" project, please contact Dr Anke Brüning-Richardson at [a.bruning-richardson@hud.ac.uk](mailto:a.bruning-richardson@hud.ac.uk).**

**The brain tumour awareness quilt was assembled and stitched by Deborah Fowler (technician) and Catherine Malkin (instructor) from the School of Design at the University of Leeds. Additional artistic input was provided by Dr Jane Scott, Senior Teaching Fellow at the School of Design.**

Deborah Fowler said: "I really enjoyed doing the project - just the thought of where all these squares had come from and what they represented. It was a labour of love for me along with everyone else who was involved. To think children had been involved too made it all worthwhile."

Ultimately, the quilt took about three days to actually assemble: a day to organize the squares to the right size; a day to sew them together and a day to create the border and the backing.



# Inspiration

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**GFME 18 years**

GFME, **Glioblastoma Foundation Michele Esnault**, established in **2001** is a French-based (Marseille), patient-oriented, support group involved in **brain tumors**. GFME translates and publishes in French **scientific publications** of Pubmed and **ASCO** on primary brain tumors. The association gives support, help, guidance on treatments and clinical trials for **adults and children** diagnosed with brain tumor. GFME works in partnership with ARTC, Brain Tumor Association For Research to raise funds. GFME is a website <http://gfme.free.fr> or <https://gfme.fr>, a quarterly magazine, a phone assistance (33) 04.91.64.55.86, and two mailing-lists ([gfme@yahoogroupes.fr](mailto:gfme@yahoogroupes.fr) and [astrocytome-gfme@yahoogroupes.fr](mailto:astrocytome-gfme@yahoogroupes.fr)). The group includes **700 patients**, care givers, **friends and family members** around the globe. For more details [gfme@free.fr](mailto:gfme@free.fr)

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You can also find us on Facebook and Messenger:  
[facebook.com/hjarntumorföreningen](https://www.facebook.com/hjarntumorföreningen)

# SIMO alla meta - Memorial Simone Luffarelli

**Marco Luffarelli**

Co-Founder, Chaos Primordiale Sports Association

On May 13, 2018 in Rome (Esquilino district), we organised the fourth edition of the event "SIMO alla meta - Memorial Simone Luffarelli", a non-competitive 5 km race.

The event was in remembrance of my brother Simone, who died in 2006, at the age of 21, from a brain tumor. Simone's smile, sympathy and the strength with which he encouraged others is the spirit with which we always organize this event.

The race in memory of Simone is organized by the CHAOS PRIMORDIALE Sports Association founded by my friend Valerio Rahim and me in 2014.

The association carries out functional and free-body training in the squares of Rome, and also participates in obstacle competitions (like the Spartan Race and OCR).

To date, "SIMO alla meta" has raised approximately € 4,000 which we have donated to the IRENE Onlus Association. The IRENE Onlus Association (based at the Istituto Regina Elena in Rome and covering neurology and neurosurgery for brain tumors) was established some years ago on the initiative of patients



Supporters of the SIMO alla meta...Memorial Simone Luffarelli gathered in the Esquilino district of Rome for a non-competitive 5 km race to raise funds for the brain tumour support organisation Irene Onlus Association at the Istituto Regina Elena.

and relatives of people with brain tumors in order to help people who receive the same diagnosis and their family members. Irene Onlus assists with health, psychological and social problems caused by the diagnosis of a brain tumour.

The activities promoted and carried out by Irene Onlus are:

- promoting information on the rights of cancer patients
- home rehabilitation (strengthening of staff for neurorehabilitation and home-based logotherapy)
- personal assistance (carers' service) in households in need of support
- psychological support for families with minors ■



Chaos Primordiale Sports Association co-founders Valerio Rahim (left) and Marco Luffarelli (right)



Simone's brother Marco (centre) and his parents, Augusto Luffarelli (left) and Stefania Baschetti (right) also supported the event



People of all ages joined the SIMO alla meta event. Pictured with the megaphone is young Simone, the son of Marco Luffarelli, co-founder of Chaos Primordiale Sports Association





## Ibadan, Nigeria walks around the world for brain tumours!

Idowu F. Adegboye, a final year medical student (aspiring to be a neurosurgical oncologist some-day), from the College of Medicine, University of Ibadan, Nigeria

DURING the International Brain Tumour Awareness Week 2018, we had the first-ever brain tumour awareness walk which was themed "Brain trek, a walk to save" here in Ibadan, Nigeria. We walked from the University College Hospital (UCH) in Ibadan to the Beere area of Ibadan (about 4.8 km) and it was really a fun time for us. Highlights of the walk were the one-on-one interaction with the populace, sharing flyers on symptoms and signs of brain tumours as well as a media broadcast on brain tumours to enlighten the general public and create awareness on brain tumours in our locale. We had great support from neurosurgeon Dr James A. Balogun and a host of other neurosurgeons at the University College Hospital, Ibadan. They were key drivers to

the success of the brain tumour awareness week and walk. They also encouraged other professional medical colleagues to donate towards awareness and the walk

by being present and participating in the walk. We are glad to donate our mileage towards global brain tumour awareness and advocacy. ■






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**Multi-disciplinary management of patients with brain tumours**  
**7 - 8 August 2019**

Venue: Wolfson Pavilion, UCT with break-out sessions at department Radiation Oncology, Groote Schuur Hospital and Red Cross War Memorial Children's Hospital

Supported in part with a grant from the Greg Wilkins-Barrick Chair in Neurosurgery and the Society for Neuro-Oncology



**SNO**  
Society for NeuroOncology




**IMPORTANT DATES:**  
**Abstract Submission closing date**  
**15 June 2019**



# ISPNO2020 in Japan

A welcome message from Dr Koichi Ichimura (ISPNO2020 Chair) and Dr Ryo Nishikawa (ISPNO2020 Vice Chair)

On behalf of the Organising Committee, it is our great pleasure to invite you to the 19th International Symposium on Paediatric Neuro-Oncology (ISPNO2020), which will take place in Karuizawa, Nagano pref., Japan in June 2020 (<http://ispno2020.umin.jp>).

The very first ISPNO was held in Tokyo back in 1986 as a small, rather private meeting. This was long before cancer genetics kicked off and flourished thanks to the Human Genome Project and next generation sequencing. Who could have imagined then that molecular analysis would become a routine clinical practice and targeted therapy would be a reality? ISPNO has now become the most prominent and distinguished scientific meeting in the field of paediatric neuro-oncology. We are tremendously honoured and thrilled to host ISPNO2020 when it comes back to where it all started 34 years ago.

## Virtually all aspects of paediatric neuro-oncology covered

ISPNO covers virtually all aspects of paediatric neuro-oncology, including diagnosis, clinical trials, novel treatment, basic and translational research, neuroradiology, psychology, quality of life, nursing and patients' care. Thanks to rapidly developing technologies, paediatric neuro-oncology has greatly advanced in the last decade. Molecular diagnostics and translational research are now an integrated part of clinical practices, and this has led to the development of novel therapies which have already saved and will benefit a number of childhood brain tumour patients. ISPNO2020 is the greatest opportunity to further push this scientific development and international collaboration toward the cure for paediatric brain tumours.

ISPNO2020 will be held from Sunday the 21st to Wednesday the 24th of June 2020. The meeting will start with the traditional Education Day, followed by the



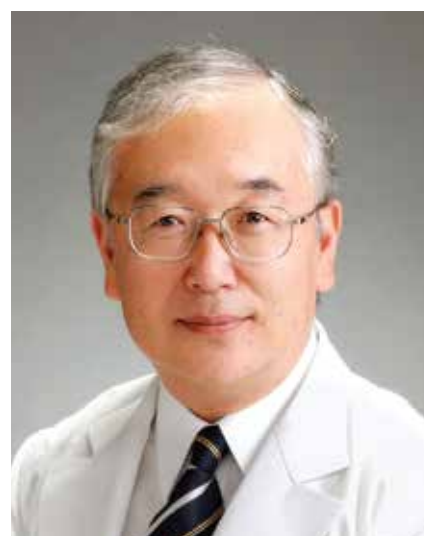
Koichi Ichimura, M.D., Ph.D, Chair of ISPNO2020, Chief - Division of Brain Tumor Translational Research, National Cancer Center Research Institute, Tokyo, Japan

main symposium that consists of a series of plenary sessions, keynote lectures, concurrent and sunrise sessions, luncheon and evening seminars as well as plenty of posters, covering all major topics on paediatric brain tumours. We welcome delegates from all over the world who wish to exchange ideas and discuss about their experiences with the international board of experts.

## ISPNO2020 is in Karuizawa

The symposium venue will be the Karuizawa Prince Hotel West. ISPNO2020 will be the first major congress the hotel will host after a sizable refurbishment, which they are very excited about. Karuizawa is a popular mountain resort, originally developed by Canadian missionary Alexander Croft Shaw in the late 19th century. Shaw was fascinated by Karuizawa's rich nature and pleasant climate, which he felt was similar to his hometown of Toronto. It has since become one of the most popular holiday destinations in Japan.

Karuizawa is located at the foot of the magnificent Mt. Asama as part of a national



Ryo Nishikawa, M.D., Ph.D, Vice Chair of ISPNO2020, Professor at the Department of Neuro-Oncology, Saitama Medical University, International Medical Center, Saitama, Japan

park. Karuizawa's forests, waterfalls and volcanic landscape offer a cosy, secluded atmosphere for the meeting away from the hustle and bustle of everyday work in the busy city. It has a rich cultural environment with numerous art galleries, museums and inspiring buildings, as well as historical houses such as Shaw Memorial Chapel. It also offers various sports facilities: golf, tennis and horse-back riding in particular. Last, but not least, Karuizawa is good for shopping!

Karuizawa is only 70 minutes away by bullet train from Tokyo station, which is 40-80 minutes from the airport on Japan's world-renowned transport network. Access for international guests in Japan will be even easier in 2020 as Tokyo is preparing for the Tokyo Olympic and Paralympic Games, another good reason to come back to Japan unless you extend your stay after the meeting. Do not miss this opportunity to visit Japan and explore its beautiful landscape, traditional architecture, and culture, particularly Japanese cuisine.

We look forward to welcoming you to ISPNO2020 in Karuizawa! ■

# ISPNO 2020

The 19th International Symposium on Pediatric Neuro-Oncology

June 21 (Sun) - 24 (Wed), 2020  
Karuizawa, Nagano, Japan

Chair: Koichi Ichimura  
Vice Chair: Ryo Nishikawa  
Venue: Karuizawa Prince Hotel West

<http://ispno2020.umin.jp/>



## EURACAN

A European Reference network (ERN)  
Helping patients with rare adult solid cancers

The **European Reference Networks** gather doctors and researchers with high expertise in the fields of rare or low-prevalence and complex diseases. They are “virtual networks” with experts who discuss the diagnosis and the best possible treatment for patients from all over Europe.

**Your doctor remains** your single point of contact if you are referred to **EURACAN**. Yet, they will have access to the EURACAN expertise, can share data, collect the experts’ input and discuss it with you at every step of the diagnosis and treatment.

**EURACAN specialists** do not only discuss individual cases. They also invest in joint research activities, work together on clinical practice guidelines and organise trainings for healthcare professionals.

**The patients are the core of the ERNs.** Patients’ organisations are key partners and played an important role in the creation of the ERNs. They help to work towards better accessibility, clinical excellence and patient outcomes.



Information video for patients and healthcare professionals



This project is funded by the European Union

Contact: Centre Léon Bérard - [muriel.rogasik@lyon.unicancer.fr](mailto:muriel.rogasik@lyon.unicancer.fr) <http://euracan.ern-net.eu> @ERN-EURACAN @EURACAN

# A Holiday Art Show 2018

## Yaron Butterfield

North Vancouver, British Columbia, Canada

A holiday art show for people with a cancer diagnosis was held on November 30, 2018 at the John Jambor room at British Columbia Cancer, Vancouver centre. The project was the inspiration of some of the BC Cancer counselling staff as well as Sara Hankinson, the BC Cancer art therapist.

The show featured works in multiple media forms and allowed patients and families a chance to get to know one another through their talents, rather than through their cancer diagnoses. I included some of my art and had the pleasure of meeting other artists, seeing their beautiful work and hearing their amazing stories. Soon I realized that within the group, four others were brain cancer survivors.

As a long term survivor, I've had the honor of supporting others going through the diagnosis. In addition to the art show, I came up with a meaningful idea. In December 2018, I decided to ask a number of Facebook brain cancer groups that I am a part of, to tell me a word or a few words that describes their experience with brain cancer. I received over 250 responses from around the world and was amazed to see the number of different words. I created this meaningful image and realized it captured feelings inside me I wasn't even aware of. I posted the image and received a number of responses such as:

"This is amazing. It's everything you feel but can't convey to people who don't understand what it feels like."

"Awesome! That is one heck of a positive message!"

"It's beautiful and really captures all of our feelings."

I kept receiving words so I updated the image, added more colour and made sure "Hope" stood out. I also made some words larger with a different colour to reflect that a particular word recurred frequently. Within the brain art, mostly positive thoughts are featured. The image is another way to express the feelings of hope, love, strength and courage that we all feel dealing with brain cancer. ■



Yaron Butterfield, glioblastoma survivor



Sara Hankinson, art therapist

The above report by Yaron Butterfield, is reprinted here courtesy of the British Columbia Cancer Agency (BCCA) and originally appeared in the BCCA's Winter 2019 edition of their *Headlines* newsletter. For more information on the work of the BCCA see <http://www.bccancer.bc.ca/health-info/types-of-cancer/brain-central-nervous-system/headlines>. To see Yaron's brain art piece, please see page 18.



# Hats for Hope

Amy Mathias

Online Community Engagement Associate, Brain Tumour Foundation of Canada

*Brain tumours need more attention. In the noise created by all the various disease groups, often armed with large budgets, it can be hard to raise awareness. Brain Tumour Foundation of Canada took a simple idea, and a Canadian national symbol, the toque (or “tuque” - Canadian knitted hat), to create a new successful awareness campaign.*

*“How a hat makes you feel is what a hat is all about.”*

Philip Treacy

award-winning haute couture milliner

Hats have long been important to the brain tumour community in Canada.

The ‘Hats Tribute’ is a feature on our website, where people affected by a brain tumour send in photos of hats that represent the many faces of the disease. Each hat pictured belongs to a diagnosed patient who has shared their courageous, often life-changing brain tumour journey.

A few years ago, a Canadian brain tumour patient was given a homemade hat when she was undergoing treatment and she made it her mission to provide hats for brain tumour patients. ‘Day by Day’s Hats for Hope’ has been a regular feature at the Brain Tumour National Conference. In 2017 she gave away 600+ hats at the Conference, collected from knitters across Canada, giving multiple hats to Support Group facilitators to take beautiful crocheted or knitted hats back to their support groups across Canada.

Inspired by both of these things and with permission from ‘Day by Day’s Hats for Hope’ as she wrapped up her program, Brain Tumour Foundation of Canada embarked on a new awareness campaign for International Brain Tumour Awareness Week in 2018. Hats for Hope had a simple premise, to encourage people to pull on a hat, any hat, to raise awareness of brain tumours.

The main day of action was October 24, 2018, the inaugural Brain Cancer Awareness



Day in Canada. There is already Brain Tumour Awareness Month (May in Canada), World Brain Tumour Day (June 8) and of course International Brain Tumour Awareness Week (October 20-27, 2018).

To be inclusive of the entire brain tumour community in Canada, we deliberately timed this new awareness day to fall in the middle of the week.

We were blown away by the response. Our social media feed was busy from morning until night with posts from across

Canada about #HatsForHope. As part of the campaign, we had encouraged meteorologists to forecast ‘Cloudy with a chance of Hats for Hope’. Singers, Olympians, TV personalities, and many more also shared a selfie with a toque on, shared their connection to the cause, and encouraged others to pull on a hat to raise awareness. Our local MP, Kate Young, also rose in the House of Commons to declare October 24th as Brain Cancer Awareness Day, showing support for our campaign at a national level. ➤

More than 450 people took part in the conversation around #HatsForHope, resulting in 188,000 impressions on social media. On October 24, 2018, there were approximately seven times more posts using #HatsForHope than those with the hashtag #BreastCancerAwarenessMonth, demonstrating that we had our share of the voice on social media that day.

People also took the initiative to organize fundraising events, such as sponsored fitness classes, contributing to beating our modest fundraising goal of a dollar for every brain cancer patient diagnosed each year in Canada (3,000).

Due to the successful nature of the campaign, the media was also actively sharing stories about the campaign, interviewing our staff, brain tumour patients, and healthcare professionals.

We are already looking forward to running the campaign again in 2019. We learned a lot this year and are grateful to everyone who sent in feedback on the campaign. We would also like to take this opportunity to thank the international brain tumour community for their messages of support. We can't wait to do it again! Watch for the campaign microsite [www.hatsforhope.ca](http://www.hatsforhope.ca) to relaunch in October 2019. ■

Learn more about the Hats Tribute:  
[www.braintumour.ca/hats](http://www.braintumour.ca/hats)  
 and Hats for Hope:  
<https://www.braintumour.ca/hatsforhope>

**About Brain Tumour Foundation of Canada:** Brain Tumour Foundation of Canada is the only Canadian national charity offering information and support to patients affected by any kind of brain tumour – be it cancerous, non-malignant or metastatic. The organization funds ground-breaking research across North America and, since 1982, has dedicated over CAD 6.9 million to finding a cure and improving treatment for brain tumour survivors. Brain Tumour Foundation of Canada is funded solely through generous contributions from individuals, corporations, organizations, employee groups and special events. Learn more at Brain Tumour Foundation of Canada's website: [www.BrainTumour.ca](http://www.BrainTumour.ca)





# It's your future...

and allied healthcare professionals are here to help you make everything of it that you can

Helen Spear

Speech and Language Therapist,

North Bristol NHS Trust and a member of the Community Therapists Network, United Kingdom

communitytherapists  
network

So, the diagnosis is brain tumour.

You won't know what the name or grade of it is until after the surgery whether that be biopsy, debulking or resection. The diagnosis remains brain tumour and things are changing.

First hit - the words 'brain tumour'. And then come the questions. What do you mean I cannot drive, how can I live this life I lead without driving? What should I tell the family? How long have I got? What did I do to get it? What should I have done to prevent this happening? Shall I alter what I eat - will that change things? Is it inherited? I should not have lived so close to those pylons; this is my phone use isn't it?

Then comes the plethora of medical language and unpronounceable drugs to prevent this, manage that. They just roll off the tongues of the professionals. It is impossible to remember what they are, least of all what they actually do. Go with it!

You feel fine so why are you going in for surgery? Feeling this good surely means there is nothing wrong and you can just leave here. But the surgeon says not. Your family say not. You know deep down inside not. So you go for it. The reassurance of knowing you are having movement or language monitored for the surgery helps. The professionalism of those around you helps but this path is rocky. You search for the old path, the smooth path, the busy-with-the-day-job path, enjoying-the-family path, planning-the-next-holiday path.

Yay, you did it! You woke up from surgery. This drink is perfection; nectar from



Speech and language therapist Helen Spear (pictured here with her husband Philip) works in the specialist area of neuro-oncology

the Gods. What is for tea? And then the 'what next' question creeps up behind you or is thrown casually into the arena by that lovely visitor who brought the chocolates.

The 'next' is going to be about getting home and facilitating living to enable coping and enable coping to facilitate living.

If you define living as 'the way in which you live your life' and coping as 'to face and deal with challenges successfully in a calm or adequate manner' then this is

what we do when we enter the 'what next' phase. Whether this is more oncology treatment, rehabilitation or just being home.

You do not have to take this path alone. There are allied health professionals (AHPs) with a wide variety of skills, knowledge and approaches to facilitate you coping with living and living with coping. They will work with your goals so that you are the empowered one and you can do as much as is possible given ➤



the extent of the problem you are facing. Our best is what we can do within the constraints of the situation we are in at this moment in time. That is all anyone can expect of you. That is what we, as AHPs, are here to help you achieve to the extent you want.

The AHPs officially include: physiotherapists, occupational therapists, speech and language therapists, clinical psychologists, dietitians and pharmacists and their support workers. They are integral to your support network along with neuro-oncology clinical nurse specialists and the various charitable organisations. Each help you to be how you want and need to be.

These guys are going to help you through the 'next' - however long.

Day by day. Week by week. You become the experts in your tumour. The AHPs are there to help when you need advice to help you maintain the expertise:

**Your sight.** You can see most things. The world looks good apar

t from that bit to the side, or the need for the patch because seeing two of these worlds is headache inducing.

**Fatigue.** That treatment was exhausting. How will I manage tomorrow and forever like this?

**That leg, that arm,** that clumsiness. I want to do so much. How do I manage? Are there exercises I can do? Are there systems that can be put in place so that I can do as much as I can, just by myself?

**Talking.** Why can't I remember that word? If they would just shut up so I can think of it. I could say something funny now but it won't be quick enough to make the impact. I want to soothe them but the words aren't there. What are they saying? My brain didn't compute that instruction; should I guess at what I should do but risk looking daft?

**Memory.** I know someone is coming today but who was it? I think I have read this page before but I cannot

remember. Where was I in making a cuppa? Was I making a cuppa?

**Reading.** It doesn't make sense. I was so into my books. What will I do now that I cannot read? I cannot stand all the rubbish on the TV.

**Writing.** I can read it but cannot write it. There must be a way.

The list of changes that can happen is longer. Someone is there who can help. Ask.

The AHPs don't just sweep in and make it better. They aim to give you some control over what is happening. They aim to give you therapy, help, guidance, advice as appropriate. They listen. They get in tune with you and your personal needs. Experience of the condition in others they have worked with helps because things that have worked for others can be suggested.

But you are in the centre. This is your life-changing diagnosis. This is your future and the AHPs are here to help you make everything of it you can. ■

### About Helen...

*I qualified as a speech and language therapist in 1987. Since then I have worked across the South West region of England, mainly between Gloucestershire and North Bristol. I have always worked with people who have acquired neurological conditions both in acute and community settings as well as working with head and neck cancer patients.*

*Since 2012 I have been working in the specialist area of neuro-oncology;*

*linking my interest in acquired neurological disorders, including language difficulties, with my interest in oncology.*

*Across my current post I work with people who have problems with swallowing, and/or language, and/or speech. I am involved in instrumental assessment clinics and have specialist interests in awake craniotomy and speech and language therapy working in palliative care.*

*I strongly believe in working with the patient as a whole; embracing their personal drivers and interests in moulding interventions resulting from informal or formal assessments. I also incorporate awareness of mental health needs into my practice, signposting patients to use mindfulness, gentle exercise, Macmillan or other cancer support centre facilities and opportunities to help them through the life changing impact of cancer.*

### About the Community Therapists Network

The Community Therapists Network is a national organisation in the United Kingdom providing information, training and education to allied healthcare professionals (AHPs) working within rehabilitation and intermediate care settings and who work across education, health, mental health and social care (local government). They

provide care and support for people living with long-term conditions.

The Community Therapists Network believes that coordinated action can be far more effective than the sum of the action from the individual people or organisations. Therefore, the Network actively encourages professionals working in all aspects of community therapy to collaborate and share knowledge, enthusiasm and best practice to stimulate advances in the care of people with long-term conditions in community and primary care.

The Community Therapists Network is a unique organisation comprised of a wide range of allied healthcare professionals. The Network exists to provide therapists with access to a range of training and educational resources. The Network runs regular events, such as workshops and conferences, which are designed to appeal to the diverse range of members.

For further information, please visit [www.communitytherapy.org.uk](http://www.communitytherapy.org.uk)

# JACOB'S HOPE FOUNDATION

- ★ We are a new advocacy organisation for brain tumour patients and people with other cancers in Cameroon, Africa.
- ★ We educate survivors and caregivers on nutrition and quality of life.
- ★ We help establish advocacy groups in our country.
- ★ We provide information and raise awareness of the challenges of brain tumours and other cancers in our Cameroonian society by using colourful visuals so that people can absorb and remember information which will help them.
- ★ We have a Facebook page - search for Jacob's Hope Foundation

**You can phone us on 00237 677 344 981**  
**You can email us at: [ngong.irene@gmail.com](mailto:ngong.irene@gmail.com)**

## WE CAN MAKE A DIFFERENCE!



**San Diego  
Brain Tumor  
FOUNDATION**

*Supporting the Needs of Patients & Families*

The San Diego Brain Tumor Foundation (SDBTF) is here to Support the Needs of Patients and their Families. We make a difference in the San Diego Community by helping patients and their families cope with having a brain tumor.

We hold monthly support groups and provide financial assistance to those that cannot work and need help in paying their monthly rent or mortgage, their medical bills, and provide groceries and gas cards to families as needed.

If you are a patient, a caregiver, or a friend call: **(619) 515-9908** or email: **[info@sdbtf.org](mailto:info@sdbtf.org)**

**[www.sdbtf.org](http://www.sdbtf.org)**



**Cure Brain Cancer  
FOUNDATION**

Finding a cure for brain cancer takes more than any one individual, organisation or nation.

### It takes a team.

We are proud to fund world-class researchers in Australia and overseas, and we advocate globally to rapidly improve outcomes for people living with brain cancer.

We won't stop until we find a cure for this brutal disease.

**Research, Advocacy & Awareness**

[curebraincancer.org.au](http://curebraincancer.org.au)

**brainstrust**  
the brain cancer people

## Here to help you live life with a brain tumour.

Receive tailored support, 24/7, whether you are a patient, carer or loved one.

Access resources and workshops to help you live better with a brain tumour.

Meet a community of people that understand life after diagnosis.



*We know.*

Not knowing what the future holds.

Call our 24/7 support line on **01983 292 405**  
email **[hello@brainstrust.org.uk](mailto:hello@brainstrust.org.uk)**  
or visit **[brainstrust.org.uk](http://brainstrust.org.uk)**

Registered charitable trust – brainstrust is a registered charity in England and Wales (1114634), and Scotland (SC044642).

# OurBrainBank - an introduction

Jessica Morris

Founder and Chair of OurBrainBank

The world of brain cancer meant, happily, nothing to me until 4:00 pm on Saturday, January 23rd, 2016.

Until that point my life was good. I was a 52-year-old Senior Vice President and Partner at FleishmanHillard, a leading global corporate public relations firm. I was living in New York City, having been born and raised in the United Kingdom. My husband and I, together with our three children, had moved here for a short stint in 2006, and had ended up staying. My husband, Ed Pilkington, is chief reporter for *The Guardian* in the United States.

In short, my life was good. I was happily married, and delighted in the way our three children were transitioning to university and adulthood.

On that Saturday, I was hiking with friends in upstate New York. I suddenly started to feel inexplicably strange, and very tired. I knew something was up, but when I opened my mouth to tell my friends, I found myself unable to speak. It was like being in a nightmare where you want to scream, but you can't make a sound. Terrifying. A few seconds later I could see my eyelids close and I was out.

I found out later that the exertion of the walk had brought on a brain bleed inside my head, squeezed by the presence of a tumor. That had triggered a full-blown seizure, which in turn revealed the mass within.

Two days later I had surgery to remove a grape-sized tumor. Two weeks later I was given the devastating diagnosis of glioblastoma – think Tessa Jowell, John McCain, Beau Biden, Ted Kennedy.

The diagnosis was - and is - terrifying, not least because the disease is considered terminal, with a median survival of 14 months. Less than 5% of those living with glioblastoma survive five years.

I'd gone from a dream life to a literal nightmare in the space of days.

I'm one of 12,000 people in the US and 2,200 in the UK given this diagnosis every year. We go from being healthy to being saddled with this awful word 'terminal'. I live in terror



Jessica Morris

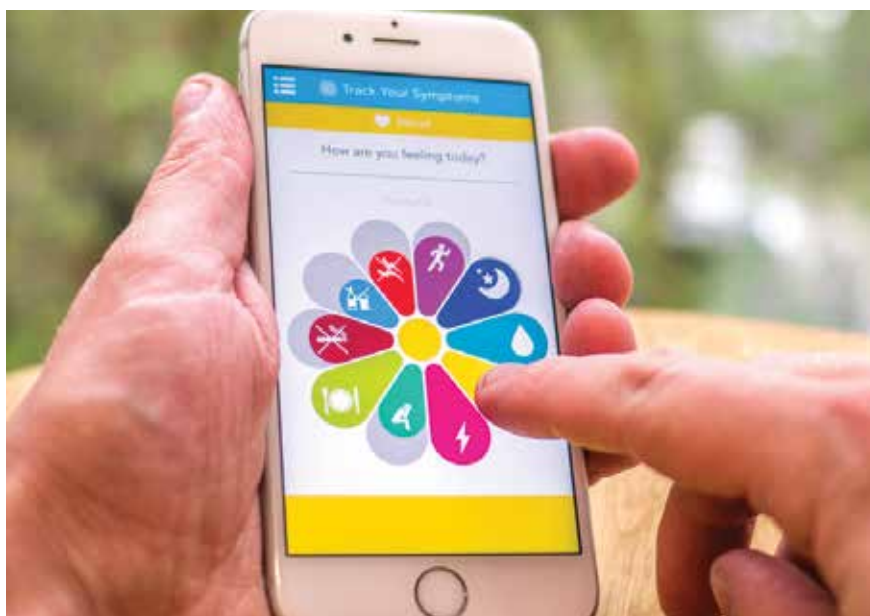
of the brain tumor's recurrence. Glioblastoma is rare, deadly, highly heterogeneous, and super-clever. It's defied years and mountains of research money, to little avail.

I trained as a historian, and have practiced as a strategic communications consultant. What that really means is that I try to understand as much as possible about something, before shaping a concerted effort

to make progress. So my instincts were and are to understand what I'm dealing with, and to meet this aggressive cancer aggressively. To live my life and not let this cancer live it. And to channel more than a quarter of a century of campaigning - from working with refugees, homeless people, disabled people, black and ethnic minorities, cities in the developing world - into turning this disease around. Where I hear about injustice and unfairness my energy accelerates, my mind focuses, ideas emerge inside me, and my determination gets me thinking.

After a few months of treatment, I asked my doctor why glioblastoma, as yet, has no cure. He explained that one of the key reasons is the difficulty in securing the scale of research funding necessary for tackling such a complex and intransigent rare disease.

While I was listening to him, I was struck by how little my experience of the various treatments I took (off trial) were documented. In contrast to regular MRIs, blood work and so forth, my symptoms were not systematically tracked. I wondered if we could enable patients like me to log our everyday, real world symptoms via an app, then perhaps researchers would be



Ten symptoms can be recorded on the app



able to derive new insights into the condition, and develop new avenues of research. At the same time, patients like me might feel more empowered, energized and hopeful by playing a more active role in documenting and thereby better managing their disease.

Soon, OurBrainBank, a new non-profit, was born. We are led by people who have been diagnosed with the disease, and those directly affected by it. We have a multi-disciplinary group of advisers, including leading neuro-oncologists, psychiatrists, nurses, neurosurgeons, dermatologists and radiologists.

The point is often made – and it is a good one – that establishment of new medical charities can divide resources and blur focus on finding cures, ameliorating suffering or campaigning for attention. OurBrainBank is acutely aware of this criticism that sometimes goes unspoken out of respect to sufferers like me.

Therefore, we are both working alongside existing charities with the intention of complementing their efforts, and creating a distinct approach to collecting data.

Ours is a model of patient-driven, patient-owned data that begins to match the vastly

expanding research universe of ‘internal’ data related to our unique genetics and immune system. If we can connect these two forms of data we believe that we have a much better chance of finding a cure.

The key tool at OurBrainBank is a free app that allows people like me and our caregivers to track our everyday symptoms, thereby managing our disease; share that data with our clinicians, thereby helping them better understand how to care for us; and donate our data to glioblastoma researchers. The app is designed by a vibrant British company, uMotif, and has been incorporated into a wide variety of user studies across many different medical conditions.

Patients and caregivers can download the free ‘OurBrainBank’ app from the App Store or Google Play, and use the code OBB100 to register. Patients own their data which is anonymized and then made available to GBM researchers subject to approval from our data access committee, chaired by Dr Fabio Iwamoto of Columbia University.

The app is currently available in the US, and we’re hoping to expand its availability to the UK and other countries as soon as our funds allow. It is certified by the New

England Independent Review Board, and every possible step has been taken to ensure patient privacy and protection.

As we grow, we’re also hoping that the app will be used to help speed up the vital clinical trial process. We are currently examining potential collaboration with three clinical trials.

In just over a year since we launched in the US, we have over 300 people using the app, with more than 5,000 data points collected. We’ve presented our initial findings at the Society for Neuro-Oncology (SNO), and we have submitted an abstract to the forthcoming American Society of Clinical Oncology (ASCO) annual meeting which has been accepted for publication online. The OurBrainBank Facebook group hosts free community video calls, where patient experts and collaborators share their ideas, their experiences, and their hopes.

We are impatient patients. We would love you to join us. ■

**For further information about OurBrainBank, please contact us at [info@ourbrainbank.org](mailto:info@ourbrainbank.org) or visit our website: [OurBrainBank.org](http://OurBrainBank.org)**

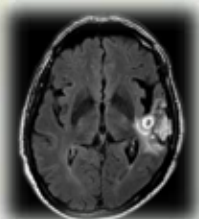


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**Northwest Bio** proudly supports the IBTA’s advocacy for brain tumor patients around the world in their battle to beat brain cancer.

Together, we can shine a spotlight on the need for new treatment options and for more clinical trials of experimental brain cancer treatments, which may provide patients and their families renewed hope and encouragement.



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# Neuro-oncology services in Nepal: a challenging and changing scenario

Dr Anish Man Singh

Consultant Neurosurgeon, Nepal Cancer Hospital and Research Center, Nepal

Nepal - officially the Federal Democratic Republic of Nepal and located mainly in the Himalayas mountain range - is a landlocked country in South Asia. Its area is 147,181 sq. km. Nepal is synonymous with majestic mountains and eight out of ten of the world's highest mountains are found within this small and beautiful country. It is the home of the world's tallest mountain, Everest, and of the birth place of Lord Buddha and the goddess Sita. It is the second richest country of fresh water with a rich cultural diversity comprising 125 different ethnic groups and castes. Nepal is a multiethnic nation with Nepali as the first language. The second language is English.

The majority of Nepalese people follow Hinduism. Buddhism is the second most-practised religion. Some people also follow Christianity, Islam and Jainism. Despite various religions, people in Nepal live in harmony by involving and celebrating each others' festivals. It



Dr Anish Man Singh, consultant neurosurgeon from Nepal

is a country where not only God, but also animals and birds are worshipped.

However, such a beautiful country was devastated by a ten-year-long civil war which ended in 2006. Additionally, a powerful earthquake in 2015 of 7.8 on the Richter scale devastated Nepal

and killed thousands of people. This greatly impacted the economy and the development of our country, including the health sector as well.

The population of Nepal is around 29 million people. The total number of medical doctors is 25,000. Among them, only 70 doctors are registered neurosurgeons. So one neurosurgeon needs to take care of 415,000 patients which is an enormous number. Well set-up hospital neurosurgery departments are centralised in the capital and some cities. Many hospitals and institutes don't have a neurosurgical department.

Today, the field of neurosurgery is emerging in Nepal but still there is a lack of dedicated neuro-oncology services. Significant challenges include: lack of referral systems between medical practitioners; lack of counselling for patients; late diagnosis and limited expertise to treat cancer.

In Nepal, the number of cancer patients is increasing day by day. In 2016-2017, the total number of new cancer patients at Bhaktapur Cancer Hospital was 15,714, out of which 2,733 (17.4%) patients underwent surgery. The total number of patients diagnosed with a brain or spinal cord tumour of the central nervous system (CNS) at the hospital in that year was 121 (0.77% primary and secondary). Out of 121 patients only 24 (19.8%) underwent



Nepal, the country of the Himalayas





The neurosurgical suite at Dr Singh's hospital in Nepal

surgery in our affiliated hospitals where our department is taking care of neuro-oncology services. Post surgical radiation therapy and chemotherapy is recommended on the basis of histopathological reports. However, immunohistochemistry (IHC) is not well practiced due to high costs and lack of availability.

CNS tumours are a very challenging entity in Nepal. The number of cases are increasing day by day worldwide. Similarly in our country, CNS tumour patients are increasing.

But providing expert health services in a resource-limited setting such as our country is a real challenge. We are sometimes bound to do neurosurgery without a microscope due to

limited logistics. In a few affiliated hospitals we have started frozen section biopsy and in the rest we are planning to do this. For immunohistochemistry (analysing for IDH1, IDH2, etc.), patients who can afford it have their tissue samples sent to a neighbouring country. We are planning to start these facilities in our own institutions in the near future.

In Nepal there is still no national health insurance system, so all health expenses are paid by patients themselves as out of pocket expenses which is a major challenge to improving the quality of the health service. However, for a few years the Ministry of Health has been providing financial aid of up to \$1000 for each newly diagnosed cancer patient.

With major challenges and limited resources, we have not compromised our neuro-oncology services for our patients. We are trying to develop all neuro-oncology services for our patients under one roof to improve patient outcomes. In the near future, we are also planing to start a professional neuro-oncology society as a sister society of the Nepalese Society of Neurosurgeons (NESON).

We know that proper health education for patients about cancer is also equally important. In Nepal, the literacy rate is 65.9%. Education plays a vital role in understanding and managing a disease. In our country, once the patient is diagnosed with cancer they promptly refuse further treatment or discontinue their follow up. With a brain tumour diagnosis, chances are even higher to refuse treatment or discontinue follow-up. This is because patients believe that all cancer is incurable and very expensive to treat. We have also seen some patients and the patient's family try to hide their disease due to the pressures of social stigma - some people think that cancer is a communicable disease. So these things regarding cancer can be addressed only with health education. Timely and early diagnosis of brain and spinal cord tumours is very important and so we need to raise awareness of these diseases and this only comes with good health education.

Neuro-oncology is a challenging domain worldwide. It is more challenging



Dance of the demon in a carnival of God

in a developing country like Nepal where we are providing our neuro-oncology services to cancer patients despite limited logistical support. So as previously mentioned above, in future we are planning to provide all of our oncology-related services under one roof. We are also focussing on creating a health insurance system to start soon.

Personally, I would like to thank the organising committee of the Society for Neuro-Oncology for providing me with a scholarship to attend and present at the SNO meeting in 2018 in New Orleans where I had the opportunity to learn more about the molecular level management of CNS tumours. And also I realised the importance of dedicated multi-disciplinary departments which can bring change for the better with regard to improved treatment and better outcomes for people with CNS tumours.

I hope one day we will be able to provide a cure for this devastating disease. So let's make efforts together to prevent and cure CNS tumours.. ■



The chariot festival of the Living Goddess, Kumari



# Spearheading the Adolescent and Young Adult Neuro-Oncology Practice Movement in India



TEENAGE & YOUNG ADULT CANCER FOUNDATION

Teenagers and young adults with brain cancer are vulnerable individuals who tend to “fall through the cracks” of access to care and the health services in India, like in many other countries.

Nearly 1100 new brain cancers are diagnosed every year in India in the age group of 15 to 29 years. Most have ill-recognized symptoms and few reach specialized multi-disciplinary centres. Experience in young adult brain tumor therapy is growing especially in large metro cities.

The emotional landscape of a young brain tumor patient is complex, the cancer often reversing the newly acquired independence from parents. The young man or woman is curious to know what is going on inside the head, but finds that friends avoid him. The teenager or young adult diagnosed with a brain tumor accepts even a frank or dismal prognosis with the classic nonchalance of a youngster and expects us to involve him or her in decisions about the illness and

treatment: quite a challenge while the parents usually tend to “hide” the diagnosis from the young person!

As yet learning the ropes of life, this young person is prone to mood swings, simultaneously dealing with gender and sexual identity, realigning social ties, and is sometimes raising a family with children of their own. The role of partner, provider and anchor, all get reversed with the disease.

The Teenage and Young Adult Cancer Foundation (TYAcan) is India's national non-profit with the mission “to give every young person with cancer a fighting chance to achieve cure, while also helping him or her live life's dream”.

TYAcan is an alliance of cancer professionals, survivors, caregivers, counselors and volunteers. It addresses childhood cancer survivors and young adults with efforts at awareness, advocacy, cancer treatment and rehabilitation. It also seeks to mitigate the phenomenon of treatment refusal. Over 65 oncologists, 100 caregivers and volunteers across ten Indian states and 16 cities are members of TYAcan.

TYAcan's advocacy has helped brain tumor patients continue their pursuits, like college studies, music and even legal and paralegal professions, sometimes all the way to the end of their struggle with the disease. The certificate hung on the wall at home, along with the braveheart's picture on the mantle, often says it all.



Dr Colonel Prakash Chitalkar, a veteran physician and oncologist from the Armed Forces, has been spearheading the Teenage and Young Adult Cancer Movement in India since 2012. His passion to improve the lives of brain cancer patients was ignited when in 1978 he was a medical intern in the army, and his mother was diagnosed with glioblastoma. His intrigue grew further, as he saw scores of soldiers and young persons in the military crossing the path of glioma and then losing the battle.

Since the inception of TYAcan, brain cancer became a focus area of the Foundation, which he serves as General Secretary. Efforts across India have borne encouraging results, like those for musician Vineet Sharma who continued performing the melodies on his flute for audiences in Kolkata, Mumbai, Jaipur and Mhow, in between his sessions of chemotherapy for recurrence at a TYAcan facility. He continued his passion for the melody all the way until two weeks before he lost his battle with glioblastoma.

The TYAcan Foundation hopes to engage with the Indian Society of Neuro-Oncology (ISNO) and the Brain Tumour Foundation of India (BTFI) to design and advocate for collaborative, multi-centre clinical trials so that more and more young patients are able to receive treatment as per evidence-based Indian guidelines.

Neuro-oncology is developing with rapid strides in India, with national centres of excellence in Mumbai, Bangalore, Chennai and Delhi raising the bar with better molecular understanding and improved surgical and radiation techniques e.g. proton beam therapy. There is a steady increase in the number of professionals joining the quest for solutions in the clinic, the operating room and in the laboratory.

The recent Indian Society of Neuro-Oncology annual meeting - ISNOCON in Bhopal (April 5-7, 2019) with 250 delegates - is a great example of our national resolve to get the better of brain cancer. TYAcan hopes to awaken both young professionals and their young patients to the limitless possibilities symbolized by the human brain even when it is diseased: the ultimate frontier of age-appropriate personalized care.

TYAcan has a hostel for patients from overseas, like Rajnesh a chartered accountant from Fiji who travelled all the way from the island nation to Indore in Western India for treatment. Obtaining support for specialized laboratory studies to find the best treatment is also one of our initiatives. TYAcan volunteers escort patients on motorcycles from outlying villages to the cancer centre. These measures have reduced treatment abandonment among brain tumour patients from nearly 80% five years ago to about 20% now.

TYAcan collaborates with the Brain Tumour Foundation of India (BTFI) and with the cancer patient survivors' group called UGAM, which means "to rise". UGAM was started in 2009 to solve education,

employment and marital issues of young cancer survivors. UGAM also creates awareness, fills the gaps and raises the possibility of wholesome support to the often-lonely young souls with cancer.

While neurosurgeons are the "captains" of the brain tumor ship in India, TYAcan engages with professionals like radiation and imaging specialists, neuro pathologists, physiotherapists and even celebrities. Round table meetings in the cities are organized and the efforts to improve the coping abilities of teenage and young adult brain tumor patients are constantly nurtured. A dialogue, then, is of essence, between the patient, caregiver and care team: to understand, to accept and to respond. ■



## Corrialmassimo per IRENE 2018

THE Corrialmassimo per IRENE 2018 edition was held in Rome, Italy on 27 October 2018 to raise awareness of the challenges of brain tumours.

Nearly 200 people, patients and their families and friends, walked for 5 km in a beautiful park, Villa Pamphili. The resultant cumulative total of 1000 km walked on the day has been "donated" to the Walk Around the World for Brain Tumours. ■



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Facebook: **Cyprus Brain Tumour Association**

## PBTN Pediatric Brain Tumour Network JAPAN

We are the network of groups of the pediatric brain tumour patients and their families in Japan, who help each other to improve our quality of life through peer support and discussion on our web site, through organising a summer camp and by appealing to the government etc.  
For more information, see the website addresses below.

### Child Brain Tumor Parents Support Group

<http://www.pbtn.jp>

### "Child Brain Stem Glioma Network"

<http://glioma-net.com/page6>

### "cranio park"

(for craniopharyngioma patients and families)  
<http://cranio-park.fc2-rentalserver.com/>

### Pediatric Brain Tumour Support Group in Kinki prefecture

<http://miracle-brain.jimdo.com/>

### Japan Brain Tumour Alliance (JBTA)

<http://www.jbta.net/>

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**Brain Tumour Research**



# An interview with Bill Tiller of the Pediatric Brain Tumor Foundation



**IBTA: What is your role at the Pediatric Brain Tumor Foundation and what does it involve?**

**Bill Tiller (BT):** I joined the Pediatric Brain Tumor Foundation as President and Chief Executive Officer in early February 2019. As President and CEO, I lead the organization in our mission to care for families along their journey, cure all childhood brain tumors, and help survivors and families thrive.

**IBTA: How has your previous work in the not-for-profit sector prepared you for your role at PBTF?**

**BT:** Prior to coming on board at the Pediatric Brain Tumor Foundation, I was the CEO of Make-A-Wish South Carolina, where my team and I had the opportunity to create hope, strength and joy by granting the heartfelt wishes of children with life-threatening medical conditions.

Working with and for these courageous children was an honor. And a truly great education. I learned a great deal about the many stressors families face when a child is critically ill. Those stressors -- such as emotional distress, financial hardship, and the challenges of navigating the health care system -- are all key areas PBTF works to address through our family support programs.

**IBTA: What led you to want to become involved in the pediatric brain tumor community?**

**BT:** There were many reasons to join the PBTF family. While at Make-A-Wish, it was impossible not to notice that more and more children with brain tumors were coming to us for support. This experience opened my eyes to the increasingly urgent need to put an end to this disease and the important role the PBTF and all of us in the pediatric brain tumor community play in equipping, educating and empowering families.

Atop the list of reasons to join the PBTF, though, was the incredible amount of passion and rigorous commitment to our mission that is demonstrated by the people who make up the organization -- from our Board of



New PBTF President and CEO Bill Tiller joined the organization in February 2019

Directors and staff to the volunteers, families, researchers and healthcare professionals we partner with. It's a community of believers who are moving our goals forward with missionary zeal and determination.

It's an exciting time to join the PBTF. I am honored to build on our founders' legacy and the recent progress we've made in research and family support to win the battle against this disease.

**IBTA: Based on what you've learned so far about the world of brain tumors, and the patient and caregiver journey, what strikes you as the three most challenging aspects of this disease?**

**BT:** While I'm not new to nonprofit leadership, I am new to the pediatric brain tumor community specifically. Three challenges I've observed so far are:

- The complexity of this disease and the staggering number of factors that can impact a child's prognosis and treatment.
- The physical, emotional, and financial stressors that affect not just the patient, but every member of the family.
- The unique and lifelong side effects pediatric brain tumor survivors face after treatment.

Observing these challenges has helped me appreciate how important it is to gather like-minded organizations to collectively invest in and direct research and family support with a longer view and bigger scope than what any one organization might be able to do alone.

**IBTA: How would you describe your approach to leadership?**

**BT:** Leadership is a moral responsibility, a sacred duty I think, which begins with values. Creating a values-based culture is paramount. Leaders define those values.

Next, leadership necessarily requires vision, and the ability to share that vision in compelling ways with the organization's various constituencies. Good leaders make the vision come alive so constituents -- staff, donors, families -- can see it, feel it, desire it. We do that by unceasingly making the case, painting the picture, so everyone can understand where we're headed and what it will look and feel like when we arrive.

We need to inspire others to internalize the vision and make it their own. Without that, all other pursuits are hamstrung.

**IBTA: What, so far, has given you the most satisfaction from your work in the pediatric brain tumor field?**

**BT:** I derive my deepest satisfaction from the testimonies of pediatric brain tumor survivors and their families. I derive my relentless drive from the testimonies of parents and siblings who've lost someone.

**IBTA: How do you relax? Do you have a hobby or a sport with which you are involved?**

**BT:** I enjoy music. I also enjoy reading and exercise. Small escapes.

**IBTA: Based on your experience to date at PBTF, what would be the first three items on your wish list for pediatric brain tumor patients and their families?**

**BT:** Aside from a cure? I wish for ➤



Pediatric Brain Tumor Foundation's Bill Tiller (left), CEO and President, and Tammy Bates (right), Southeast Regional Director, visiting the brain tumor team at the Aflac Cancer and Blood Disorders Center at Children's Healthcare of Atlanta - Scottish Rite Hospital, USA.

connection. I wish for peace. I wish for hope. Connection to other families, to resources, to information. Peace for the struggle, for the loss. Hope for the journey forward.

**IBTA: What kind of innovative, best practice models would you like to see embedded in pediatric brain tumor support?**

**BT:** I'd like to see organizations make investments to accelerate their fundraising. If we are passionate about our mission – and we are – we must be passionate about funding the mission.

In order for the PBTF to invest boldly in the most promising research initiatives and provide the requisite care and support to children and families, we have to accelerate

revenue. Transformational outcomes require investment. We have to build our organizational capacity to raise money.

Our fundraising structure will be the lattice upon which our mission will grow. Our fundraisers have to gather the resources necessary to transform research and transform lives.

Part of increasing fundraising capacity is moving intentionally into relational fundraising. We must nurture and steward deep, personal relationships with our donor investors. Certainly, transactional fundraising has purpose and place, but relational giving will be the path to growth and long-term sustainability.

**IBTA: Is there anything else you would like to add?**

**BT:** During my short time in this community, I have been impressed by the incredibly warm welcome of its members... from my team at the PBTF to the researchers, advocates, families and other organizations I have met as I've stepped into this role. I am grateful for the experiences and perspectives they've shared with me, and I look forward to leading the PBTF as we continue to partner with others in the brain tumor community. ■



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# Brain tumour awareness in Portugal

Andreia Capela

Medical Oncologist, Centro Hospitalar Vila Nova de Gaia / Espinho, Portugal

Centro Hospitalar Vila Nova de Gaia / Espinho, Portugal celebrated International Brain Tumor Awareness Week 2018 with activities that brought patients, families and professionals together.

We distributed posters in wards, waiting rooms and hospitals promoting awareness as to what brain tumors are, their symptoms and signals, and some facts relating to their pathology. With this activity we engaged in awareness-raising to professionals from all other medical areas and also patients coming to the hospital during International Brain Tumour Awareness Week.

An e-mail was sent to all professionals in our institution as well as the primary care institutions in our area of influence, notifying them about the Awareness Week and the activities to be held.

On 25th October 2018 we organized a couple of sessions dedicated to patients and families. The afternoon started with a presentation of the Professional Rehabilitation Center from Gaia and a testimonial of one of our patients who took their physical and neurocognitive rehabilitation program.

Following this session, the group was divided into two groups: patients and families. A stretching session for primary brain tumor patients was led by our



Andreia Capela, Centro Hospitalar Vila Nova de Gaia/Espinho, EPE

rehabilitation nurses. It was an interesting experience where patients got to help one another and some even overcame some of their difficulties and limitations.

In parallel we held an information and sharing session for families which was led by our mental health specialist nurse. After discussions about the limitations of these patients and some ideas on how to deal with this, family caregivers were invited to share their experiences and how they

have overcome their challenges. The most touching moments were felt when families revealed how they felt useless and how terrifying it was to receive the diagnosis of a brain tumour. They also talked about how they now live their lives focussed on the patient's needs and how a future of hopes and planned activities had to be adjusted.

A social worker, oncology nurses and an oncologist were present to answer any questions. The discussions highlighted that there was a great need for more social and psychological support and this request was made to the professionals.

At the end of the afternoon all participants joined together to share a brunch. An invitation to visit and contact the Rehabilitation Center was sent to patients and families.

Attendance at the sessions on 25th October was low but the event was full of meaning and value for those who were present. This makes us believe that we accomplished our main purpose: to be there for patients.

During next year's awareness week we and our patients will be on board again. CHVNG/E supports this cause! At CHVNG/E we take care of you. We thank patients and families, CHVNG/E professionals, Centro de Reabilitação Profissional de Gaia, Nutricia and Liga de Amigos do CHVNG/E. ■



The IBTA's magazine, *Brain Tumour*, was available for patients and caregivers to take away



During International Brain Tumour Awareness Week, all participants at the brain tumour patient and family sessions at the Centro Hospitalar Vila Nova de Gaia in Espinho, Portugal joined together to share a brunch



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# An interview with Professor Jérôme Honnorat, President - EANO 2019 Congress in Lyon, France

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**IBTA: Where did you spend your childhood?**

**Jérôme Honnorat (JH):** I spent my childhood in the center of France, along the river Loire, in Burgundy, in a small village in the south of Nevers. Nobody knows this region although it's very nice. Sport and walks in the forest were my daily life.

**IBTA: Did you come from a family environment that had a connection with medicine or research?**

**JH:** There is a family medical tradition and many of my ancestors were psychiatrists in Paris, but my father was a materials engineer. The family scientific tradition was nevertheless very strong especially in the veterinary and medical sciences and my father was the director of the research department at SAFRAN for the construction of aircraft engines.

**IBTA: What attracted you to medicine and to the brain tumor arena specifically?**

**JH:** The medical studies were obvious after my first graduation because of my attraction to biology. Neurology was imposed after my medical studies because at that time there was little knowledge of neurological disease mechanisms, only a few treatments were available and research was obviously necessary. My studies quickly coupled medical and scientific training. Brain tumors were a later passion when it came to choosing a university career. There was no structure dedicated to neuro-oncology in Lyon despite the presence of a neurological hospital. My first meeting with Professor Martin van den Bent in Rotterdam in 1994 lead me to think about a neuro-oncological structure. I was alone in the beginning to construct a neuro-oncology department in Lyon which now includes five neuro-oncologists for 21 hospital beds and a day hospital.



Professor Jérôme Honnorat

**IBTA: Do you anticipate any significant breakthroughs in brain tumor therapies in the next ten years? If so, in what area?**

**JH:** Over the past 15 years, tremendous progress has been made in characterizing the molecular biomarkers of brain tumors. The knowledge on prognosis and evolution, according to these biomarkers, is now considerable. In the next ten years, I am convinced that specific treatments based on these biomarkers will emerge. We also hope that immunotherapies will develop.

**IBTA: As the Head of Service in your hospital in Lyon, what is at the top of your wish list for brain tumor patients in your care?**

**JH:** Naturally first - to improve overall survival and have a multitude of different treatments, all effective. We must also think about quality of life and improve the management of neurological disorders and disability induced by the tumor and treatments, including cognitive disorders that are not always well taken into account. Care must not be limited to the hospital, and appropriate support

structures are needed for the well-being of patients outside the hospital environment.

**IBTA: What inspires you in your research work?**

**JH:** Curiously, I find the inspiration to develop my research in other scientific disciplines such as archeology, history or anthropology. Changing one's way of thinking is essential to properly address one's scientific domain. I learned from archeology that the gaps were as important as the presence of the object. Archeologists are able to rebuild a house that disappeared based on the presence of the pole holes that outline the contours of what no longer exists. The same must be done with research on brain tumors. We must not only think about what we see, but also about what is absent.

**IBTA: What do you anticipate some of the highlights will be at EANO 2019 in Lyon?**

**JH:** The Lyon 2019 EANO Congress will be particularly interesting because we are at a crossroads in the field of brain tumors and waiting for the results of several clinical trials. The emergence of immunotherapies is an important point. The identification of biomarkers continues to grow and we better understand the molecular events leading to the development of tumors. The congress will also be the time to discuss the role of surgery in glioblastomas. Should a greater emphasis be placed on neurosurgery or should systemic treatment take the biggest role?

**IBTA: As the EANO 2019 Congress President, what three things would you like to accomplish with the conference?**

**JH:** (1) Ensure a very high scientific level allowing the emergence of new ideas for the treatment of brain tumors; (2) attract a large audience from across Europe for fruitful and

constructive exchanges; and (3) make Lyon known to the greatest number of people who can then appreciate this city and come back

**IBTA: What would be your main message to healthcare professionals, allied healthcare professionals and brain tumour patient advocates who are considering attending EANO 2019 in Lyon?**

**JH:** To meet, discuss and exchange points of view is an essential element of progress. Diversity is the guarantee of progress towards improving quality of care. All European systems are not identical and each has specific care that can feed and improve the care of others. My message is simple. Come many, from all the countries of Europe to discuss your practices. You will return to your countries with ideas and concepts that will improve care and transform the lives of patients.

We hope that all European neuro-oncologists and a large number of colleagues from other continents will be present in Lyon for a maximum of scientific interactions and allow the emergence of new ideas for the treatment of patients.

We will be very happy to welcome them to this millenary city steeped in history with renowned gastronomy and which is particularly pleasant in September

**IBTA: We note that there is a session planned for EANO 2019 on patient reported outcomes. Briefly, what are your thoughts on PROs in neuro-oncology? Are they valuable? What are the challenges associated with them?**

**JH:** Medicine is changing and the patient must be at the center of our concerns. For a long time the doctor took a place bigger than the patient who, for the medical team, was often reduced to his or her illness. We must change perspectives. The patient as a whole must be the center of our efforts. In this perspective, PROs are essential. This is a particularly strong challenge in neuro-oncology, however, due to neurological disorders and the rapid evolution of glioblastomas. However, this is an essential approach that must be developed in all centers. A specific session is needed at EANO.

**IBTA: How do you relax when not at work? Do you have a special hobby?**

**JH:** I like reading, including history books and all kinds of novels. Sport and especially skiing occupy me during the winter in the Alps which are very close to Lyon. In the summer, walks in the mountains are a way to recharge my batteries. ■

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# Rare Cancers Europe (RCE) celebrates ten years of determined advocacy

On Tuesday 25 September 2018 - in the European Parliament in Brussels, Belgium - Rare Cancers Europe (RCE) celebrated ten years of active work and took stock of its achievements in addressing rare cancers as well as discussing the way forward in tackling the challenges that persist for rare cancers.

This high-level anniversary event - jointly organised by RCE, the European Society for Medical Oncology (ESMO) and *The Parliament Magazine* and hosted by Members of the European Parliament (MEPs) Alojz Peterle and Lieve Wierinck - highlighted RCE's European milestones in addressing rare cancers, particularly its involvement in the establishment of the Joint Action on Rare Cancers (JARC) and the European Reference Networks (ERNs).

IBTA Chair and Co-Director, Kathy Oliver, moderated one of the discussion sessions. Speakers at the Parliamentary event included Paolo Casali (Chair, Rare Cancers Europe and medical oncologist at the Istituto Nazionale Tumori, Milan), Annika Nowak (Member of Cabinet of the Commissioner for Health and Food Safety, Vytenis Andriukaitis) Alojz Peterle (MEP), Lieve Wierinck (MEP), Francesco de Lorenzo (President, European Cancer Patient Coalition), Cristian-Silviu Busoi (MEP) and Ortwin Schulte (Permanent Representation of the Federal Republic of Germany to the European Union).

Discussions centred around current challenges faced by the European Reference



Networks and what more needs to be done to improve standards of care and reduce administrative barriers for patients crossing European borders for medical care. The problems of generating and exploiting evidence on rare cancers was also discussed along with the potential impact of the EU draft Regulation on health technology assessment and improving treatment options for rare cancer patients while helping safeguard the sustainability of EU healthcare systems. ■

Photos by Jean-Yves Limet







Hannah and Rob Smith participated in the annual Astro Brain Tumour Fund Holkham Hall Family Walk. They were walking in memory of Hannah's friend, Gemma Barrett, who died from a brain tumour.



The Astro Brain Tumour Fund annual Holkham Hall walk is a real family occasion. Pictured here are Karen and Abby Warne and family.



Tristan and Claire Cork and family walked in memory of their son Finnbar who had a brain tumour. Finnbar is the inspiration behind the charity that the Corks set up – Finnbar's Force.

## Norfolk Family Walk, UK

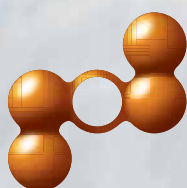
Mary Burton, Treasurer of the Astro Brain Tumour Fund wrote to the IBTA to report about their annual family walk. She said:

"Over 350 adults and children plus numerous four-legged friends converged on Holkham Hall on Sunday, 7th October 2018 for the Twelfth Norfolk Family Walk, organised by Astro Brain Tumour Fund, in aid of brain tumour research and support.

"The weather started off a little chilly but later the sun broke out and the walk was much enjoyed by all.

"Many participants had been touched by brain tumours, including patients and families and friends and the walk is a lovely way to celebrate their lives. Over 1,900 miles were walked and we raised over £7,500. The mileage total will be added to the 2018 "Walk Around the World for Brain Tumours" which is a project of the International Brain Tumour Alliance." ■

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# Who cares?

Lena Davidsson, Mariella Delgado and Eskil Degsell  
Svenskahjartumorföreningen (Swedish Brain Tumour Association)



Lena Davidsson



Eskil Degsell



Mariella Delgado



**W**ho do you care about and who cares about you?

That question and that answer are very relevant and useful during the brain tumour journey, not only for the person who has the disease but also for loved ones, informal caregivers and professional healthcare providers.

We know from studies that social relationships have an impact on our health and wellbeing. We also know from our own lived experiences that being diagnosed with a brain tumour often leads to the need for a lot of coordinated care between caregivers, healthcare providers and social care. We know that sometimes when coordination of care fails that it can lead to serious problems and we know that sometimes it's really hard for us, as patients and caregivers, to see what is actually missing, as we have never been on an illness journey like this before and we have to learn along the way.

Rajiv Mehta, as its Principal Investigator, designed and conducted the year-long Atlas of Caregiving Pilot Study which led to the creation of the Atlas of Caregiving. The Atlas explores "the everyday practice of family caregiving... applying new methods to collecting, analysing and presenting detailed contextual data about the lived experience of providing care." The creators of the Atlas of Caregiving believe that "...improving outcomes for caregivers depends just as much on understanding their relationships and networks as it does on understanding their behaviors." ([www.atlasofcaregiving.com](http://www.atlasofcaregiving.com)). The project recognises that the real experts in caregiving are the caregivers and the families themselves.

So at the Swedish Brain Tumour Association (Svenskahjartumorföreningen), we decided to see if we, as a patient organization together with healthcare providers, could explore how CareMapping might influence the quality of social relations and communication with healthcare professionals, and how this could impact on health-related quality of life for the patient and caregiver. We also agreed that if the CareMaps work well, we should endeavor to embed this

intervention into clinical practice to help support those affected by a brain tumour.

Thanks to funding and shared knowhow from the Regional Cancer Centre in Stockholm-Gotland and the Swedish Cancer Society we have now embarked on a fascinating exploratory phase of CareMapping.

We have started to do several workshops where we explore how different people react and reflect on expressing themselves through drawing and using CareMaps. We decided early on in the project to involve a broad range of people in our workshops so we invited people with brain tumours, loved ones, caregivers and former caregivers to people who had passed away from their brain tumour.

At first, we thought that we could simply do a workshop and, by the end of it, draw a complete CareMap. But we learned early on that it takes time to make a good CareMap and just by starting this process one also encourages a lot of reflections. So we explained to people how to create a CareMap during the workshop and then made plans to meet up again at a future date and discuss their experiences.

We have gathered many valuable insights from our work with CareMaps so far:

- Existing social relationships tend to change in the presence of a brain tumour. Quite often a “new” core social network is created. To see, value and act on good, solid relationships seems

to be very important in the presence of a brain tumour in many ways.

- New relationships with healthcare providers occur and the quality of the relationship with them is important .
- People with brain tumours, loved ones, caregivers and family and former

caregivers of deceased people tend to use the CareMap in different ways.

- Everyone has their own unique situation and therefore all CareMaps look different.
- There are, however, some aspects and situations during the brain ➤

### Instructions

**Use a black pen**

1. Start by filling in the box in the right corner.

**Use a blue pen**

2. Draw yourself and the ones you live with in the house in the middle of the map. Add pets if you have any.
3. Draw people you care about outside your household and drag connecting arrows from you to them.
4. Draw communities you care about (e.g. facebook groups, sports club, work colleagues) and drag connecting arrows from you to them.
5. Use the characters to describe how you experience each relationship, how important it is to you and how often you have contact.
6. Draw additional people and communities who care about you and add connecting arrows from them to you (could be the same as those that you care about).

Legend:

- Person: Circle
- Community/Group: Triangle
- Pets: Dog icon
- Health and social care provider: Square
- Relationship strength: Double line = Strong, Single line = Weak, Wavy line = Complicated, Dashed line = Neutral
- Importance: 1 = Not so important, 2 = Quite important, 3 = Very important
- Frequency: D = Daily, W = Some times/week, M = Some times/month, Y = Some times/year, R = Rarely

**Use a red pen**

7. Draw people and communities who help you cope with your injury/illness and add connecting arrows from them to you.
8. Draw health and social care providers who help you cope with your injury/illness and add connecting arrows from them to you.
9. Use symbols to describe how important the relationships are to you and how often they help you.

➡ If you have a long-term injury and/or illness, please continue with points 7-9. ➡

There are many different ways to use the map and no way is wrong. You can fill in all parts or just a few. You can choose to share the information with others or keep the map for yourself. The tool can be used once, several times or regularly. You decide yourself how you want to use it!

**Note:** this is the Swedish test version of instructions which we have used when we are exploring the concept of CareMapping. Some modifications of the Atlas of Caregiving have been done to better fit Swedish culture.

### What is CareMapping?

CareMapping is used to strengthen families and communities and is a useful tool for demonstrating with simple line drawings how the dynamics work between patients, families, caregivers, healthcare professionals and others one would meet on life's journey. These relationships are all the more crucial when one is faced with a serious illness such as a brain tumour.

Here is a further description from the Atlas of Caregiving website about CareMapping:

“Caregiving happens within a web of relationships of relatives, friends, professionals, and organizations. People are often simultaneously caring for

themselves, caring for others, and being cared for by others. What each person does varies by ability and context, and over time.

“An Atlas CareMap is a drawing and a process for self-reflection and action, which also provides a catalyst for conversation. It is a diagram of a person's care ecosystem, drawn by hand or computer, showing who cares for whom, and how. The process of thinking about and drawing an Atlas CareMap has helped people to more clearly see and to better understand their existing care ecosystem. For many, this has led to action and/or changes in perception resulting in stronger ecosystems, better care and more confidence in managing their care situation. Many have also found great value in sharing their maps with others,

as they discover they have so much to gain, emotionally and practically, from sharing their respective care experiences and knowledge.

“...Since an Atlas CareMap is fundamentally a diagram of “Who cares for whom?”, it is important to define what counts as “care”. We provide some suggestions... But in the end, it is your Atlas CareMap, you get to decide what counts.”

A booklet and guide on CareMapping is available on the Atlas of Caregiving website which can teach you how to draw and use the Atlas CareMaps.

Find out more about CareMapping by visiting <https://atlasofcaregiving.com/caremap/>



tumour journey that people with brain tumours and their loved ones and caregivers feel are the same for each other. For those who had lost family members to a brain tumour, explanations of how they thought, felt and acted when facing different crossroads and situations were also brought to light using CareMaps.

■ Hopefully, as our CareMapping project progresses we will find new and innovative ways to capture how people affected by brain tumours feel, think and act in real time so we can better understand the lived experience.

■ A lot of people at our workshops reflected on the relationships with their children. We learned that this is also an area which we need to explore much more and in collaboration with researchers and healthcare providers develop more and better interventions so we can promote good inter-generational relationships and detect possible difficulties and challenges in the family dynamic earlier.

We have also received funding from the Swedish Research Council for Health, Working Life and Welfare in collaboration with the Karolinska Institute, one of the world's foremost medical universities and Sweden's single largest centre of medical academic research. This helps to really give us the potential not only to explore and develop CareMapping but also to do more research into this important area. We now have a PhD student working with us and are also recruiting post-doctoral students for the project as well.

We will continue to explore the use of CareMaps and we are now also starting to do workshops with healthcare providers to see how they can use the information we discover. Our work will take us up to at least 2025 and we really hope that more people join us on this journey and can contribute to our knowledge bank and share experiences with us. ■

**Please do feel free to contact us  
at [eskil@degssell.com](mailto:eskil@degssell.com)**



Raise awareness of  
the challenges of brain  
tumours - plan an  
event for International  
Brain Tumour  
Awareness Week 2019  
(26th October to  
2nd November)



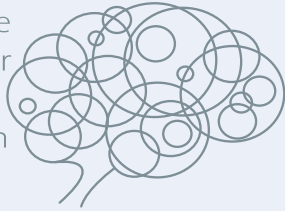
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patients!

[www.asate.es](http://www.asate.es) [info@asate.es](mailto:info@asate.es)

**CBTA** Childhood Brain Tumor Association of Taiwan

We are Childhood Brain Tumor Association of Taiwan  
Our mission is to help brain tumor children to improve a  
better quality of life.



For more information, visit:

[www.cbta.org.tw](http://www.cbta.org.tw)  
[cbta.taiwan@msa.hinet.net](mailto:cbta.taiwan@msa.hinet.net)  
[www.facebook.com/cbta.org.tw/](https://www.facebook.com/cbta.org.tw/)



**WERKGROEP HERSENTUMOREN vzw**  
**STUDY GROUP BRAIN TUMOURS**  
**BELGIUM**  
**GROUPE D'ETUDES DES TUMEURS**  
**CEREBRALES**



Information, Contact, Awareness, Advocacy

Gasstraat 5, B-2950 Kapellen

[www.wg-hersentumoren.be](http://www.wg-hersentumoren.be)  
[info@wg-hersentumoren.be](mailto:info@wg-hersentumoren.be)



Brain Tumor  
Patient and Caregivers' Association  
Turkey

**Keeping The Hope Alive  
Across Continents**

[www.beyintumoru.org](http://www.beyintumoru.org)

.inform  
.educate  
.support



[/beyin.tumoru](https://www.facebook.com/beyin.tumoru)



[@beyintumoru](https://twitter.com/beyintumoru)

# The 7th Brain Tumor Awareness Day in Argentina

Alejandra T Rabadán, MD, PhD, IFAANS

Chief of Division Neurosurgery, Institute of Medical Research A Lanari. University of Buenos Aires. U.B.A.

THE Section of Neurooncology of the Argentine Society of Cancerology organized the "7th Annual Brain Tumor Awareness Day" on 10th August 2018 in the Abasto Hotel, Buenos Aires. It was held in conjunction with the 7th Symposium of the Section of Neuro-oncology and the 2018 Argentine Meeting of Cancerology. The Argentine Association of Neurosurgery (AANC); the Latin American Federation of Neurosurgical Societies (FLANC); and the Society for Neuro-Oncology Latin America (SNOLA) also gave academic support to the meeting.

Representatives from different disciplines (ie neurosurgery, neuro-oncology, radiation therapy, psycho-oncologists, palliative care) participated. We focused on advances in stereotactic radiosurgery. Speakers from different disciplines gave lectures: Dr Diego

Hernández (neurosurgeon); Dr Máximo Barros (radiation therapy); and Dr Diego Prost (clinical oncologist). Round table participants included Dr Gustavo Ferraris (President, Argentine Society of Oncologic Radiation Therapy, SATRO); Dr Ana M Martínez (Vice President, SATRO); Dr Alejandro Muggeri (clinical oncologist) and Dra Alejandra Rabadán who discussed aspects of radiosurgical treatment for metastases. We were honoured to have with us the world-eminent Prof Osvaldo Betti, the pioneer of LINAC radiosurgery in Argentina and a key world player in this field.

At the Brain Tumor Awareness Day event it was also announced that we are working with the AANS/CNS Section on Tumors to develop a fellowship in the United States for young Argentinian neurosurgeons. The

AANS/CNS Tumor Section, together with the CNS Foundation, started the International Observership Program (IOP), which provides an Argentinian neurosurgeon the opportunity to participate as an observer for three months in a US center. The rotation focuses on all tumors of the central nervous system, with participation in clinics, conferences, surgeries, and consultations. The inaugural observership was in fall/winter 2018 and consisted of a scholarship/grant of US \$25,000 (including air travel, accommodation and expenses during the observership). ■

**For more information on the observership in the US, visit:**  
**[www.cns.org/InternationalObservership](http://www.cns.org/InternationalObservership)**



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# Comment:

## Social media in the brain tumour space

Dr Abhishek Puri

Attending Consultant, Department of Radiation Oncology, Fortis Hospital, Mohali, India.

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The diagnosis of a brain tumour is devastating. During this time of distress, confusion and anxiety, families need a roadmap to guide them effectively. The standard of care and support is different across the various parts of the world and this often leads to disparities in outcomes. Overburdened healthcare systems leave little time even with the most empathic physicians to guide affected families effectively. Hence, often the common solution for patients and their caregivers to obtain answers and support is to join online virtual communities and social networks.

It is imperative to understand these networks and to use these resources efficiently especially in the context of maintaining individual privacy.

The need for a social connect is fundamental to humankind. The Internet has eased these connections by erasing geographic boundaries. Email, instant messaging, virtual chat rooms and message boards/forums were the forerunners of social media and are still present in some form or other. Facebook made its debut in 2007 and gradually gained mass acceptance.

Twitter has also become very popular now with many users. It started out as a medium for sharing links and “micro-blogging” in less than 140 characters (dubbed “tweets”). However, Twitter recently increased its word limit for tweets as well as added some additional features, allowing for longer messages, photos and videos. Twitter has become popular with many brain tumour organisations and patient advocates who maintain an active presence there. The downside of Twitter, for some users, is that it is confusing for novices although this is not a significant barrier for use.



Dr Abhishek Puri

Try a Twitter search for “brain tumour organisations”. You can also limit your search geographically under “advanced search”. The listed names in search results are accounts that you can follow. Each account starts with the prefix “@”. Whenever you post a tweet that includes the prefix @username, that user gets a notification. It is akin to calling out to a specific individual in a noisy room and is typically used to bring someone’s attention to something or it can also be used to start a conversation.

The tweets from accounts which you are following will start appearing in an area on your screen called a “timeline”. The next step is to search for specific “hashtags”. These are words or phrases (without spaces) added to a message to identify it to a particular topic. For example, for brain tumours, common hashtags that are used include: #GBM, #btm #fightGBM #gliomas #braintumours etc. All tweets related to these hashtags appear in search as well as the accounts

using them. The use of hashtags has proven so popular that it is a feature that has now been incorporated into other social media platforms, such as Facebook.

Another way to use Twitter is to make public or private lists. A list is a curated group of Twitter accounts. It is quite common for people to follow hundreds or even thousands of other Twitter accounts, and lists are a convenient way to categorise the wealth of information to make it manageable. You can create your own lists or subscribe to lists created by others. A public list will notify the account that the individual is part of the list, and other people will be able to find and follow your list. For example, you can name your list as “a brain tumour” and add all related accounts to it. It will list tweets separately from your main timeline. It is the best way to organise the flow of information.

Instant messaging services, such as WhatsApp, are familiar to many users. The company is now owned by Facebook, which governs its privacy policies. WhatsApp connects individuals via their mobile phone number, which is a potential drawback by creating a risk for harassment and identity theft. It does, however, allow for easy communication between individuals and groups without the need for creating a social media account. Another messaging solution might be to use the Telegram chat application. While the basic layout is similar to WhatsApp, Telegram has Twitter-like functionality in groups. Telegram has channels that work as public broadcast lists. You can forward or copy links to specific posts to discuss it in the groups. Telegram also supports hashtags and “@” prefixes, just as in Twitter, and it has a robust privacy model. ■

# Focus on activities in Japan



The IBTA attended and presented at the Non-Communicable Disease (NCD) Global Forum for Civil Society on Cancer in Tokyo, Japan in November 2018 organised by the Health and Global Policy Institute (HGPI).

On Tuesday, 6th November 2018, the IBTA was honoured and delighted to participate in the Tokyo-based Health and Global Policy Institute's (HGPI) Non-Communicable Disease (NCD) Global Forum for Civil Society on Cancer.

HGPI is a not-for-profit health policy think tank, based in Japan and working to help citizens shape health policies by generating policy options and bringing stakeholders together as a non-partisan group to discuss various challenges in this arena.

The Global Forum on Cancer event was held at the historic Gakushikaikan Hall in Tokyo and involved patient advocacy leaders, healthcare professionals, members of academia and industry from Japan and also abroad. The Forum was sponsored by Bristol-Myers Squibb K.K., Edwards Lifesciences Corporation and Novo Nordisk Pharma Ltd and supported by the Japan Chronic Disease Self-Management Association (J-CDSMA) and Partnership to Fight Chronic Disease (PFCD).

Lively presentations, workshops, deliberations on cross-cutting topics in cancer and panel discussions took place at the Forum. IBTA Chair and Co-Director Kathy Oliver spoke to the topic of "Cancer Policy and Patient Voices from a Global Perspective" highlighting examples in the brain tumour and rare cancer fields. Kathy emphasised the crucial importance of considering what matters most to patients in creating clinical trials, treatments and support opportunities. She also addressed some of the issues of rare cancers such as misdiagnosis, unequal access to treatments,

insufficient numbers of clinical trials and other challenges. She included examples of the All.Can global initiative which highlights concrete ways to ensure sustainable cancer care by reducing inefficiencies in cancer care and improving patient outcomes.

While in Tokyo, Kathy also met with brain tumour patient advocacy colleagues Laureline Gatellier (President, Japan Brain Tumour Alliance/IBTA and Board Member of Rare Cancers Japan/RCJ) and Yuko Moue (President, Pediatric Brain Tumor Network of Japan and Board Member of Rare Cancers Japan/RCJ). ■



IBTA Chair and Co-Director Kathy Oliver participated in a panel discussion on "Patient Involvement in Cancer Policy-Making for Sustainable Healthcare Systems".

# Patient insights for sustainable care - improving efficiency in care for all

## All.Can at the European Health Forum Gastein 2018

All.Can is an international initiative set up to identify ways to optimise the efficiency of cancer care by focusing on improving outcomes for patients.

With the growing burden of cancer and financial pressures on our health care systems, there is an urgent need to improve efficiency in cancer care. Improving efficiency is not a question of linear cost-cutting – but of finding ways to allocate resources more efficiently to achieve better outcomes for patients. This will require tough decisions, and thinking in terms of long-term investments rather than short-term policy fixes.

The All.Can initiative comprises leading representatives from patient organisations, policymakers, healthcare professionals, research and industry, all of whom contribute their time for free to the initiative.

The work of All.Can involves leading and commissioning research to gather evidence on where system inefficiencies exist and to help identify ways to improve efficiency in cancer care. All.Can also develops concrete tools and platforms for stakeholders to work together to ensure cancer care decisions are focused on what matters most to patients, and resources are used as effectively as possible. Finally, All.Can helps to implement concrete policy actions based on these findings.

### All.Can at the European Health Forum Gastein

At the 21st European Health Forum Gastein (EHFG), which took place in October 2018, the international All.Can initiative - in which the IBTA serves on the Steering Committee - hosted a session titled 'Patient insights for sustainable care – improving efficiency in care for all'.

During the session, multi-stakeholder attendees were invited to suggest policy changes and real-world solutions to tackle the issues identified in the international All.Can patient survey. The patient survey was launched in early 2018 to gain patients'

insights into where they had encountered inefficiencies in their cancer care, to inform All.Can's recommendations on where policy changes should be made.

Lieve Wierinck, Member of the European Parliament (MEP), a member of both All.Can international and the MEPs Against Cancer (MAC) group, gave a keynote introduction for the session via video to highlight the need to improve efficiency, share learning and benchmark best practice across Europe. Kathy Oliver, All.Can member and co-founder of the International Brain Tumour Alliance, moderated the session.

### All.Can workshop and panel discussion

The All.Can session at EHFG consisted of a group workshop and panel discussion. Attendees were split into groups, and each group was asked to consider a real patient quote from the survey to identify practical solutions to the problems raised by the patient. Groups were then given two minutes to 'pitch' their ideas as if talking to policymakers or other key decision-makers, with panel members asked to respond to the ideas suggested.



IBTA Chair and Co-Director Kathy Oliver moderated the All.Can session at the European Health Forum Gastein, Austria in October 2018

Many interesting ideas were described about how patient-identified inefficiencies can be tackled to improve cancer care. All.Can will be taking the thoughts and recommendations generated from the session, and incorporating them into their policy implementation phase of work in 2019 and beyond. ■

**The full findings from the All.Can patient survey are expected to be released at the end of June 2019 on [www.all-can.org](http://www.all-can.org).**



Speakers from the All.Can session in Gastein. From left to right: Daniel Ratchford, Quality Health; Zeger Vercouteren, Johnson & Johnson; Kathy Oliver, the International Brain Tumour Alliance (IBTA); Xavier Franz, Varian Medical Systems; Yolande Lievens, European Society for Radiotherapy and Oncology (ESTRO) and European CanCer Organisation (ECCO); Dirk van den Steen, European Commission DG Santé; Stefan Gijssels, Digestive Cancers Europe



# Bucaramanga's International Brain Tumour Awareness Week Activities

Gabriel Vargas MD

Honorary President of the Neurological Oncology Section of the Latin American Federation of Neurosurgical Societies (FLANC) and lead coordinator of the 8th Symposium

For the eighth year in a row we supported the International Brain Tumour Awareness Week 2018 with four different activities in Bucaramanga, Colombia.

The VIIIth International Brain Tumour Awareness Day Symposium was held on Saturday 3rd November at the Universidad de Santander (UDES) with more than 350 participants. Physicians, health personnel interested in the topic, students, patients and their families attended the event.

We had a great scientific meeting with the support of many international speakers via web conferencing and many local professors from Cali, Bogotá and Bucaramanga. Neurosurgeons, neurologists, neurophysiologists, pathologists, radiotherapists, oncologists, anesthesiologists, surgical instrumentation students and students from the neurosurgery research group gave lectures during the day discussing diagnosis, current treatments and care of patients with brain tumours.

At the end of the event, patients with brain tumours also had a brief space to present thoughts and feelings about their lives and experiences during the whole process of treatment for their tumours.

All of the activities were supported by the Universidad de Santander (UDES) and its medical faculty, Clínica Chicamocha, Hospital Universitario Los Comuneros, SNOLA ( Society of Neurooncology Latinoamérica ), Section of Neurooncology and Skull base of the Colombian Association of Neurosurgery (ACNcx), Section of Neurooncology of the Federación Latinoamericana de Neurocirugía (FLANC) and different commercial partners involved in the treatment of patients with brain tumours. The event was free for everyone. ■

**VIII SIMPOSIO DÍA INTERNACIONAL DE LA CONCIENTIZACIÓN EN TUMORES CEREBRALES**  
BUCARAMANGA - COLOMBIA / SABADO 3 DE NOVIEMBRE DE 2018

**AUDITORIO YARIGÜES - UDES CAMPUS LAGOS DEL CACIQUE**  
8:00 a. m. - 2:00 p. m.

**EVENTO PRE-SIMPOSIO**  
Taller de Cirugía de Base de Cráneo en 3D para Especialistas.  
Lugar: Edificio Arhuaco Piso 1 - UDES Campus Lagos del Cacique Salón Ciber-Anatomy.  
Fecha: Noviembre 2 de 2018.  
Hora: 7:00 a 8:30 pm.

**IBIA INTERNATIONAL BRAIN TUMOR ALLIANCE**  
EN APOYO A INTERNATIONAL BRAIN TUMOR AWARENESS WEEK 2018

Informes Simposio:  
[www.neurocirugiaoncologicafanc.blogspot.com](http://www.neurocirugiaoncologicafanc.blogspot.com)  
(+57) 316 626 2081 / (+57) 7 - 638 97 57  
Transmisión vía Streaming en [www.udes.edu.co](http://www.udes.edu.co)

Tema: Avances en tratamiento de tumores cerebrales  
Entrada Libre  
Dirigido a: Personal de salud interesado en el tema, estudiantes, pacientes y familiares

Logos: Capítulo de Neurocirugía Colombiana, SNOLA, LOS COMUNEROS, Clínica Chicamocha S.A., Capítulo Neurooncología y Base de Cráneo.



Dr. Alvaro Campero from Argentina coordinated a pre-symposium course on skull base surgical approaches aimed at neurosurgeons and the neurosurgery research group from the Universidad de Santander. There was a 3D video presentation which is why everyone is wearing special 3D glasses.



Neurosurgery research group students from the Universidad de Santander (UDES) participated in the XV City of Bucaramanga Marathon. During the event they were promoting the VIIIth International Brain Tumour Awareness Day Symposium.



Oncologist Dr. Olavo Feher from Sao Paulo, Brasil (President of the Society for Neurooncology Latinoamerica - SNOLA) and neuropathologist Dr. Fernando Velandia from Bogota, Colombia led a dinner discussion between neurosurgeons, radio-therapists and oncologists. The main aim was to create strategies for multidisciplinary treatment of brain tumour patients.



David Hetherington Memorial Walk of Hope in London



Portsmouth Walk of Hope

## Walks of Hope mega day for Brain Tumour Research

Saturday 29th September 2018 was a mega day for the Brain Tumour Research charity in the United Kingdom. It held six Walks of Hope across the country from Scotland to the south coast: Loch Lomond, Litherland, Milton Keynes, London, Portsmouth, and Bridgwater and Taunton.

The first-ever Portsmouth Seafront Walk of Hope saw a pink army of more than 200 people walk along the coast in either 4.3 or 7.2-mile walks. The event raised a fantastic GB £5,900 to help give hope to the 16,000 people a year diagnosed with a brain tumour in the UK.

In London's Queen Elizabeth Olympic Park, the David Hetherington Memorial Walk of Hope was led by David's wife, Shaz. David sadly passed away from a brain tumour in November 2016 at the age of 39, leaving Shaz and two young children.

Shaz was joined by fellow supporters from the charity's Power of David Fundraising Group and the walk raised a tremendous GB £8,000!

Shaz said: "I'm delighted that the Walk of Hope was such a success and that so many people turned out to help us fundraise. Many of us are inspired by David's memory but we were also walking in honour of the hundreds of thousands of people who suffer daily from this disease. We can't sit back and let this situation continue."

The money raised through the Walks of Hope will help sustain the ground-breaking research taking place at the Brain Tumour Research Centres of Excellence in London, Portsmouth and Plymouth as well as influencing the UK government to invest more in brain tumour research.

The charity is already planning its 2019 Walks of Hope. The date is set for Saturday 28th September and there will be even more walks this year.

For more information on the Walks of Hope visit [www.braintumourresearch.org/walks-of-hope](http://www.braintumourresearch.org/walks-of-hope) ■

# Brain tumour patient and caregiver advocacy, support, fundraising and information organisations and initiatives

## AUSTRALIA

### ACT Brain Tumour Network

Email [btaa@shout.org.au](mailto:btaa@shout.org.au)  
or call Susan on 0404255156

### Adult Brain Cancer Support Association

[adultbraincancersa@gmail.com](mailto:adultbraincancersa@gmail.com) <https://www.facebook.com/AdultBrainCancerSA?fref=nf>

### Australian Pituitary Foundation

<http://www.pituitary.asn.au/>

### Brain Tumour AhoyHoy

<http://www.braintumourahoyhoy.org/>

### Brain Tumour Alliance Australia (BTAA)

[www.btaa.org.au](http://www.btaa.org.au)

### Brain Tumour Association Western Australia

[braintumourwa@hotmail.com](mailto:braintumourwa@hotmail.com)  
<http://www.btawa.com.au/>

### Brain Tumour Support Group - Cancer Council Queensland

<https://cancerqld.org.au/get-support/>  
or <https://cancerqld.org.au/get-support/cancer-emotional-support/brain-tumour-support/>

### Cure Brain Cancer Foundation

<http://www.curebraincancer.org.au>

### Grey Matters

[www.greymatters.org.au](http://www.greymatters.org.au)

### Mark Hughes Foundation

<https://markhughesfoundation.com.au/>

### Neuro-Oncology Information Network - NOgin

<http://www.sydneybrainandspinesurgeons.com.au/nogin.html>

### Newro Foundation

<http://www.newrofoundation.com.au/>

### Peace of Mind Foundation

<http://www.peaceofmindfoundation.org.au>

### Robert Connor Dawes Fund

<http://rcdfoundation.org/>

### United Brain Tumour Support

Contact Pete McLaughlin:  
(Australia) 0422 784885.  
Listing here also: <http://www.yourcare.com.au/supplier/profile/united-brain-tumour-support>

## BELGIUM

### Can cé tu

<http://www.cance-tu-asbl.eu>

### Werkgroep Hersentumoren

<http://www.wg-hersentumoren.be>

## CAMEROON

### Jacob's Hope Foundation

<https://www.facebook.com/Jacobs-Hope-Foundation-for-Brain-tumours-and-other-cancers-1735452683351613/>

## CANADA

### BC Cancer Agency

<http://www.bccancer.bc.ca>

### B-Strong

<http://www.bstrong.ca>

### b.r.a.i.n.child

<http://www.sickkids.ca/Brainchild/index.html>

### Brain Tumour Foundation of Canada

[www.braintumour.ca](http://www.braintumour.ca)

### Gerry and Nancy Pencer Brain Tumor Centre

<http://www.pencerbraintrust.com/>

### Meagan's Walk:

Creating a Circle of Hope  
[www.meaganswalk.com](http://www.meaganswalk.com)

### Tali's Fund

[www.taldoron.com](http://www.taldoron.com)

## CAYMAN ISLANDS

### Brain Tumour Foundation (Cayman Islands) "The Forgotten"

<http://www.btfcaymanislands.com>

## CROATIA

### Croatian Brain Tumor Association - GLIA

[www.glia.hr](http://www.glia.hr)

## CYPRUS

### Cyprus Brain Tumour Association (CBTA)

<https://www.facebook.com/cbta.cyprus>

## DENMARK

### HjernetumorForeningen

<http://www.cancer.dk/hjernetumorforeningen/>

## FRANCE

### Alinoe

(Association Lilloise de Neuro-Oncologie)  
[www.alinoe.asso.fr](http://www.alinoe.asso.fr)

### ARTC Paris

<http://www.artc.asso.fr/>

### ARTC Sud

[www.artcsud.fr](http://www.artcsud.fr)

### ARTC Toulouse – Midi Pyrenees

<http://www.artc.asso.fr>

### Association Léa Princesse Eternelle

<http://leapourlavie.free.fr/>

### GFME Glioblastoma Fundation Michèle Esnault

<http://gfme.free.fr/>

### Imagine for Margo

<http://imagineformargo.org/en>

### Oligocyte Bretagne Ouest

<https://assoligocyte.wordpress.com/association/>

### Oscar's Angels

[www.oscarsangels.com](http://www.oscarsangels.com)

## GERMANY

### Deutsche Hirntumorhilfe eV

[www.hirntumorhilfe.de](http://www.hirntumorhilfe.de)

## INDIA

### Brain Tumour Foundation of India

[www.braintumourindia.org](http://www.braintumourindia.org)

## IRELAND

### Brain Tumour Ireland

<http://www.braintumoureireland.com/bti/>

### The Irish Brain Tumour Support Group

[www.braintumoursupport.ie](http://www.braintumoursupport.ie)

## ITALY

### Associazione Italiana Tumori Cerebrali ONLUS

<http://www.tumoricerebrali.it/>

### BrainLife

[www.brainlife.org](http://www.brainlife.org)

### Il Fondo di Gio ONLUS

[www.ilfondodigio.it](http://www.ilfondodigio.it)

### IRENE Onlus

<http://www.associazioneirene.it/>

### Italia - Glioblastoma Multiforme - cancro al cervello

<https://www.facebook.com/Italia-Glioblastoma-multiforme-cancro-al-cervello-57560022151/>

## JAPAN

### Japan Pediatric Brain Tumor Network

[www2.pbtn.jp](http://www2.pbtn.jp)

### Japan Brain Tumor Alliance

<http://www.jbta.org>

## LEBANON

### CHANCE - Children AgaiNst CancEr

<http://www.beirut.com/l/25407>

## LITHUANIA

### Kartu Lengviau

[www.kartulengviau.lt/joomla/pradzia.html](http://www.kartulengviau.lt/joomla/pradzia.html)



## NETHERLANDS

### Hersentletsel.nl

<http://www.hersenletsel.nl>

### Hersentumor.nl

<http://hersentumor.nl/>

### STOPhersentumoren.nl

[www.stophersentumoren.nl](http://www.stophersentumoren.nl)

## NORWAY

### Hjernesvulstforeningen

[www.hjernesvulst.no](http://www.hjernesvulst.no)

## PHILIPPINES

### Philippines Brain Tumour Alliance

<http://www.facebook.com/pages/Philippine-Brain-Tumor-Alliance/139492062749160/>

## SINGAPORE

### Brain Tumour Society (Singapore)

<http://braintumoursociety.org.sg>

## SOUTH AFRICA

### Rainbows and Smiles

<http://www.rainbowsandsmiles.org.za>

## SPAIN

### Asociación Española de Afectados por Tumores Cerebrales - ASATE

<http://www.asate.es/>

### Fondo Alicia Pueyo - The Alicia Pueyo Fund

[www.fondoaliciapueyo.org](http://www.fondoaliciapueyo.org)

## SWEDEN

### Swedish Brain Tumor Association

(Svenska hjärntumörföreningen)

[www.hjartumorföreningen.se](http://www.hjartumorföreningen.se)

## SWITZERLAND

### Kinderkrebs Schweiz

<http://www.kinderkrebshilfe.ch>

### Schweizer Hirntumor Stiftung

(Swiss Brain Tumor Foundation)

<http://www.swissbraintumorfoundation.com>

## TAIWAN

### Childhood Brain Tumour Association of Taiwan (CBTA)

<http://www.cbta.org.tw>

## TURKEY

### Türkiye Beyin Tümörü Hasta ve Yakınları Demegi (Brain Tumour Patient & Caregivers' Association of Turkey)

<https://www.facebook.com/tbthyd/>

## UGANDA

### Uganda Brain Tumour Foundation

<http://www.ubtuf.org>

## UNITED KINGDOM

### Ali's Dream

[www.alisdream.co.uk](http://www.alisdream.co.uk)

### Andrew McCartney Trust Fund

[www.andrewmccartneyphotos.co.uk](http://www.andrewmccartneyphotos.co.uk)

### Anna's Hope

[www.annashope.co.uk](http://www.annashope.co.uk)

### Astro Brain Tumour Fund

[www.astrofund.org.uk](http://www.astrofund.org.uk)

### Brain and Spine Foundation

[www.brainandspine.org.uk](http://www.brainandspine.org.uk)

### Brain Tumour Action

[www.braintumouraction.org.uk](http://www.braintumouraction.org.uk)

### Brain Tumour Research

[www.braintumourresearch.org](http://www.braintumourresearch.org)

### Brain Tumour Research and Support Across Yorkshire

<http://www.btrs.org.uk>

### Brain Tumour Research Campaign

<http://www.wayahead-btrc.org/>

### Brain Tumour Support

[www.braintumoursupport.co.uk](http://www.braintumoursupport.co.uk)

### Brain Tumour Support Group - St Thomas' Hospital, London

<http://www.guysandstthomas.nhs.uk/our-services/cancer/cancer-types/brain/patients.aspx>

### Braintrust

[www.braintrust.org.uk](http://www.braintrust.org.uk)

### Brainwaves Brain Tumour Support Group

<http://www.brainwavessg.co.uk/>

### Brainwaves NI (Northern Ireland)

[www.brainwaves-ni.org](http://www.brainwaves-ni.org)

### British Acoustic Neuroma Association - BANA

[www.bana-uk.com](http://www.bana-uk.com)

### BT Buddies

[www.btbuddies.org.uk](http://www.btbuddies.org.uk)

### Charlie's Challenge

[www.charlieschallenge.com](http://www.charlieschallenge.com)

### Clowns in the Sky

<http://www.clownsinthesky.org/>

### East Kent Brain Tumour Support Group

<https://www.facebook.com/EKBTSG/>

### Ellie's Fund - Brain Tumour Trust

[www.elliesfund.com](http://www.elliesfund.com)

### Fighting Ependymoma

<http://www.fightingependymoma.org.uk>

### Headcase

[www.headcase.org.uk](http://www.headcase.org.uk)

### Katie McKerracher Trust

[www.katiemckerrachertrust.co.uk](http://www.katiemckerrachertrust.co.uk)

### Levi's Star

<http://www.freewebs.com/levisstar/>

### Meningioma UK

[www.meningioma.uk](http://www.meningioma.uk)

### Naseem's Manx Brain Tumour Charity

<http://www.naseemsmnxbraintumourcharity.co.uk/>

### PPR Foundation

<http://www.thepprfoundation.com/>

### Spinal Cord Tumour Forum

[www.spinalcortumour.org.uk](http://www.spinalcortumour.org.uk)

### Taylan's Project

[www.taylansproject.com](http://www.taylansproject.com)

### Teenage Cancer Trust

[www.teenagecancertrust.org](http://www.teenagecancertrust.org)

### The Brain Tumour Charity

[www.thebraintumourcharity.org](http://www.thebraintumourcharity.org)

### Thorne Mason Trust

<http://www.thornemasontrust.co.uk/>

### Tuberous Sclerosis Association

[www.tuberous-sclerosis.org](http://www.tuberous-sclerosis.org)

### Worcestershire Brain Tumour Support Group

<http://www.braintumoursupport.co.uk/worcestershire.html>

## UNITED STATES

### Accelerate Brain Cancer Cure

[www.abc2.org](http://www.abc2.org)

### Addi's Faith Foundation

[www.addisfaithfoundation.org](http://www.addisfaithfoundation.org)

### Adult Ependymoma

<https://sites.google.com/site/adultependymoma/>

### A Kid's Brain Tumor Cure (AKBTC)

<http://akidsbraintumorcure.org>

### American Brain Tumor Association (ABTA)

[www.abta.org](http://www.abta.org)

### Angels Among Us

[http://dccc.convio.net/site/PageServer?pagename=angels\\_home](http://dccc.convio.net/site/PageServer?pagename=angels_home)

### Ben and Catherine Ivy Foundation

[www.ivyfoundation.org](http://www.ivyfoundation.org)

### Benny's World

<http://www.bennysworld.org/>

### Brad Kaminsky Foundation

[www.tbkf.org](http://www.tbkf.org)

### Brain Candy Project

[www.braincandyproject.org](http://www.braincandyproject.org)

### Brain Science Foundation

[www.brainsciencefoundation.org](http://www.brainsciencefoundation.org)

### Brain Tumor Foundation

[www.braintumourfoundation.org](http://www.braintumourfoundation.org)

### Brain Tumor Foundation for Children

[www.braintumorkids.org](http://www.braintumorkids.org)

### Brain Tumor Fund for the Carolinas

<http://www.btfnc.org/about/overview.cfm>

### Brain Tumor Support Group of Northeast Florida

<http://resources.caregiver.com/listing/brain-tumor-support-group-of-northeast-florida.html>

**Brains Together for a Cure**

[www.brainstogetherforacure.org](http://www.brainstogetherforacure.org)

**Brian Bedell 2 Young Foundation**

<http://www.2yf.org>

**BT Survivor Online Group**

[www.btsurvivor.com](http://www.btsurvivor.com)

**California Brain Tumor Association**

<https://www.facebook.com/The-California-Brain-Tumor-Association-217285898326170/>

**Central Brain Tumor Registry of the United States**

<http://www.cbtrus.org/>

**Central New Jersey Brain Tumor Support Group - CNJBTS**

[www.njbt.org/startCNJBTS.cfm](http://www.njbt.org/startCNJBTS.cfm)

**Charles Warren****Brain Tumor Awareness Foundation**

[www.charleswarrenfoundation.org](http://www.charleswarrenfoundation.org)

**Childhood Brain Tumor Foundation**

[www.childhoodbraintumor.org](http://www.childhoodbraintumor.org)

**Children's Brain Tumor Foundation**

[www.cbtf.org](http://www.cbtf.org)

**Chordoma Foundation**

<http://www.chordomafoundation.org>

**Collaborative Ependymoma Research Network (CERN) Foundation**

<http://cern-foundation.org>

**Cullather Brain Tumor Quality of Life Center**

<http://cullather.org/>

**Dr Marnie Rose Foundation**

[www.drarnierose.org/](http://www.drarnierose.org/)  
<https://www.facebook.com/drarnierosefoundation/>

**Emory Brain Tumor Support Group**

[www.neurosurgery.emory.edu/BTSG/contact.htm](http://www.neurosurgery.emory.edu/BTSG/contact.htm)

**Ependyaparents online support group**

<http://braintrust.org/groups/ependyaparents/>

**Epidermoid Brain Tumor Society (Online)**

<http://epidermoidbraintumorsociety.org/>

**Florida Brain Tumor Association**

<http://www.floridabraintumor.com/homepage.htm>

**Gray Matters Foundation**

[www.graymattersfoundation.com](http://www.graymattersfoundation.com)

**Head for the Cure Foundation**

[www.headforthecure.org](http://www.headforthecure.org)

**Healing Exchange Brain Trust**

<http://braintrust.org>

**Jeffrey Thomas Hayden Foundation**

[www.jthf.org/](http://www.jthf.org/)

**Just One More Day:**

<http://dipg.blogspot.co.uk/>

**Kevin J Mullin Memorial Fund for Brain Tumor Research**

[www.lemonhead.org/](http://www.lemonhead.org/)

**Kortney Rose Foundation**

<http://thekortneyrosefoundation.org/>

**Lauren's Foundation**

<http://laurensfoundation.org/fitzys-5k-run/>

**Legacy Brain Foundation**

<http://www.legacybrainfoundation.com/>

**Making Headway**

[www.makingheadway.org](http://www.makingheadway.org)

**Mark Linder****Walk for the Mind**

<http://www.marklinderwalkforthemind.org/>

**mASS Kickers**

<http://www.masskickers.org/>

**Matthew Larson****Pediatric Brain Tumor Research Foundation**

[www.ironmatt.org](http://www.ironmatt.org)

**Matthew's Miles**

<http://www.matthewsmiles.org/>

**Meningioma Mommas**

[www.meningiomamommas.org](http://www.meningiomamommas.org)

**Michael G Belz Foundation**

<http://mgbf.org>

**Michael Quinlan Brain Tumor Program/****Brain Injury Association of Kentucky**

[www.biak.us](http://www.biak.us)

**Monmouth and Ocean County****Brain Tumor Support Group**

[www.njbt.org/startMOCBTSG.cfm](http://www.njbt.org/startMOCBTSG.cfm)

**Musella Foundation for****Brain Tumor Research and Information, Inc.**

[www.virtualtrials.com](http://www.virtualtrials.com)

**National Brain Tumor Society**

[www.braintumor.org](http://www.braintumor.org)

**Nick Gonzalez Foundation****for Brain Tumor Research**

<http://thenickgonzalesfoundation.org/>

**Oklahoma Brain Tumor Foundation**

[www.okbtf.org](http://www.okbtf.org)

**Pediatric Brain Tumor Foundation**

<http://www.curethekids.org/>

**ROC On! Run Over Cancer**

<http://www.roconnow.com/>

**San Diego Brain Tumor Foundation**

[www.sdbtf.org](http://www.sdbtf.org)

**Sontag Foundation and Brain Tumor Network (BTN)**

<https://sontagfoundation.org>

<http://www.braintumornetwork.org>

**Southeastern Brain Tumor Foundation**

<http://sbtbf.org/>

**Students Supporting Brain Tumor Research (SSBTR)**

<http://www.ssbtr.org/>

**Team Billy**

[www.teambilly.org](http://www.teambilly.org)

**The Caroline Fund**

<http://www.carolinefund.org>

**The Cure Starts Now Foundation**

[www.thecurestartsnow.org](http://www.thecurestartsnow.org)

**The Tanner Seebaum Foundation**

[www.tannersfoundation.org](http://www.tannersfoundation.org)

**Tug McGraw Foundation**

<http://www.tugmcgraw.org>

**Voices Against Brain Cancer**

[www.voicesagainstbraincancer.org](http://www.voicesagainstbraincancer.org)

**Walk for Kate and Blankets for Brains**

<http://www.walkforkate.org/about.html>

**Western North Carolina Brain Tumour Support**

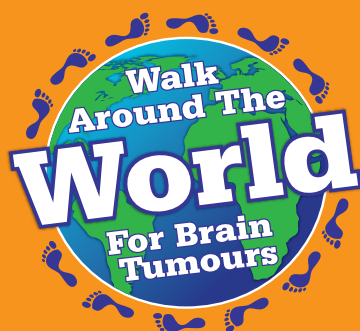
[www.wncbraintumor.org](http://www.wncbraintumor.org)

**ZIMBABWE****Zimbabwe Brain Tumor Association (ZBTA)**

<https://www.facebook.com/Zimbabwe-Brain-Tumor-Association-225796887464934/>



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[www.theibta.org](http://www.theibta.org)

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 The International Brain Tumour Alliance