

Brain Tumour

You are not alone on this journey...

**From surviving to thriving:
a model of brain cancer
survivorship care at UCSF**

**Survey finds disparities in
care of patients with
metastatic brain tumours**

**TRK inhibitors
for CNS tumours**

**Our cover
story...
Why Brainy?**

- Improving patient reported outcome assessment in clinical care and studies
- A day in the life of a brain tumour patient's nurse navigator
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Stories from our international brain tumour community:
United States, Germany, Switzerland, New Zealand, Canada, The Netherlands, United Kingdom, Ireland, Kenya, Brazil, Australia, France, India, Norway



International Brain Tumour Awareness Week 2021



International Brain Tumour Awareness Week 2021

The 2021 International Brain Tumour Awareness Week will take place from Saturday, 30th October to Saturday, 6th November 2021

The annual International Brain Tumour Awareness Week is your chance to highlight the challenges of brain tumours in your own country. We encourage you to organise an activity which will contribute to increased awareness about brain tumours. For example, it could be a walk, a picnic, an information seminar, a scientific conference, a coffee morning, the distribution of a media statement or whatever you think will help to publicise the brain tumour cause and highlight the need for a special response and an increased research effort.

Please register/report your Awareness Week activity by completing this form: <https://theibta.org/sign-up-for-an-event/#awareness>

For more information please visit www.theibta.org or contact kathy@theibta.org

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Published by
The International Brain Tumour Alliance (IBTA)
Editorial
Kathy Oliver (Editor-in-Chief)
Magazine Design
Edwina Kelly Design (edwina@edwinakellydesign.co.uk)

Printed by
Warners Midlands Plc, Bourne, Lincolnshire, UK
www.warners.co.uk

Cover
Cover photo credit: greenmarketing.it

Copy
With warm thanks to all our contributors, interviewees and colleagues in the international brain tumour community

Brain Tumour is published by the International Brain Tumour Alliance (IBTA), a not-for-profit, limited liability company incorporated in England and Wales, company registration number 6031485.

International Brain Tumour Alliance (IBTA)
PO Box 244, Tadworth, Surrey, KT20 5WQ, United Kingdom
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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,

It's been another year of lockdowns, masks, social distancing, little or no travel, and a range of other restrictions caused by the continuing threat of the COVID-19 pandemic. But thanks to the determined efforts of researchers, scientists, pharmaceutical companies, clinical trial investigators and trial participants, regulators and others, the development and approval of a variety of effective vaccines against COVID-19 has brought light at the end of a very long, dark tunnel.

In 2020, the IBTA in conjunction with the Society for Neuro-Oncology (SNO) ran an international survey on "Brain tumours and COVID-19: the patient and caregiver experience" which was published (free access) in the journal *Neuro-Oncology Advances* (<https://doi.org/10.1093/oaajnl/vdaa104>). Results from a second IBTA survey on the effects of COVID-19 on brain tumour patient advocacy charities/not-for-profits was also published in *Neuro-Oncology Advances* (free access via <https://doi.org/10.1093/oaajnl/vdaa166>).

Despite the challenges of COVID-19 - and as you will read in this year's *Brain Tumour* magazine - the international brain tumour community remains incredibly determined to not stand still and to continue to do their best to bring support, information, new treatments and hope to patients and their families.



With best wishes,

Kathy Oliver

Chair, International Brain Tumour Alliance (IBTA)

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We wish to thank the following for their support of the IBTA's work this year.



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Around the World with the IBTA

The IBTA has contacts in 112 countries around the world to whom it makes available its free annual magazine, *Brain Tumour*. We print between 11,000 and 14,000 copies of *Brain Tumour* magazine each year and send them for free to recipients in these countries. We also publish the magazine digitally on www.issuu.com

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.

Brain Tumour magazine has readers in the following countries:

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From Surviving to Thriving: A Model of Brain Cancer Survivorship Care at the University of California, San Francisco (UCSF)

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According to the US National Cancer Institute (2018), “an individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life”.¹ Brain cancer survivorship has become an increasingly important area for neuro-oncology clinical care and research as medical advances in screening and treatment have increased rates of brain cancer survival.

Brain cancer survivors constitute a vulnerable population with distinct and complex medical, psychosocial, emotional, and cognitive needs. These needs often change throughout the disease journey, negatively impact quality of life, and add additional distress to caregivers and loved ones. Increased awareness about the wide range of short and long-term effects of brain cancer and its treatment and the significant impact these have on one's quality of life and function, has led

to more attention on survivorship issues faced by brain cancer patients.

General cancer survivorship resources often fall short in meeting the unique needs of brain cancer survivors, but efforts such as the creation of a neuro-oncology survivorship care plan (SCP) are now emerging to address this.² The SCP was designed to be a communication tool to help foster and share better understanding of follow-up care after active treatment. Furthermore, the SCP provides recommendations to help anticipate future needs as it pertains to potential long-term cancer and treatment effects, secondary malignancies, and psychosocial issues.³

Planning a survivorship program: our efforts started with listening to the patient voice

In 2018, a donor with a vision and intention to support young adults

with brain cancer offered a generous philanthropic donation which was matched with funds from the University



Sheri Sobrato Brisson – donor, entrepreneur,
and philanthropist

continued ►



Figure 1 – UCSF Sheri Sobrato Brisson Brain Cancer Survivorship Program. Our patients shared that many never thought they could live full productive lives beyond the limitations of their diagnosis. They made the distinction that surviving to do what is necessary to live despite hardships was not the same as thriving. To bridge the gap between surviving and thriving, a dedicated multidisciplinary survivorship team was formed. Drawing upon the collective expertise of the team has allowed the survivorship program to offer resources, education, support, and connection to help survivors thrive and live their best lives. Original illustration by Noel Sirivansanti, 2021.

of California, San Francisco (UCSF) Helen Diller Comprehensive Cancer Center. As a result, the UCSF Sheri Sobrato Brisson Brain Cancer Survivorship Program was developed, a one-of-a-kind program to better meet the needs of adults living with a primary brain cancer diagnosis (<https://braintumorcenter.ucsf.edu/supportive-care/sheri-sobrato-brisson-brain-cancer-survivorship-program>).

With a lack of existing neuro-oncology survivorship models to guide program development, it was important to understand patients' lived experiences by hearing from them directly. Semi-structured interviews and focus groups with UCSF brain cancer survivors were conducted. During the interview process, two key questions were asked: "what does it mean to live a great life with brain cancer?" and "how can we (UCSF) support you in doing so?"

Survivors expressed issues with adapting to their "new normal", coping with lingering side effects and symptoms, role changes, disruption of family systems, fear of cancer recurrence, social isolation, and the search for renewed meaning, purpose, and hope. Yet many voiced a

deep gratitude and appreciation for their life, as well as a desire to give back while they still could. Although survivors were continuing to live, they were not thriving. Thus, the survivorship program responded to these issues by providing an array of holistic, patient-centered services to help empower survivors to be the healthiest version of themselves.

The program connects survivors to opportunities, support, services, and to other members of their community, acting as a bridge between surviving and thriving (Figure 1). The program also enriches clinical care at UCSF by aligning and complementing with other existing neuro-oncology supportive resources such as palliative care, social work, and the UCSF Gordon Murray Neuro-Oncology Caregiver Program (<https://braintumorcenter.ucsf.edu/supportive-care/ucsf-neuro-oncology-gordon-murray-caregiver-program>).

Mission of the program

The mission of the Sheri Sobrato Brisson Brain Cancer Survivorship Program is to enhance the wellness and quality of life of patients with brain cancer through a collaborative,

multidimensional approach focusing on emotional, physical, and cognitive health. A dedicated survivorship team was formed consisting of a medical director, family nurse practitioner, and program manager. The survivorship team also includes key collaborating partners: a social worker; a neurosurgeon; an integrative oncologist who specializes in nontraditional therapies alongside conventional treatments like surgery, chemotherapy and radiation; palliative care specialists; outreach and clinic liaisons; an exercise physiologist; and neuropsychologists.

Pillars of the program with a brief description

To provide survivors with the best, individualized survivorship care possible, all survivorship services and resources have been designed to meet a wide range of survivor needs at different time points of the journey and patients are able to utilize them at any time. Guided by the program's mission statement and survivor input, the team constructed a comprehensive approach to brain cancer survivorship wellness emphasizing seven pillars of support [Figure 2] which are briefly outlined.

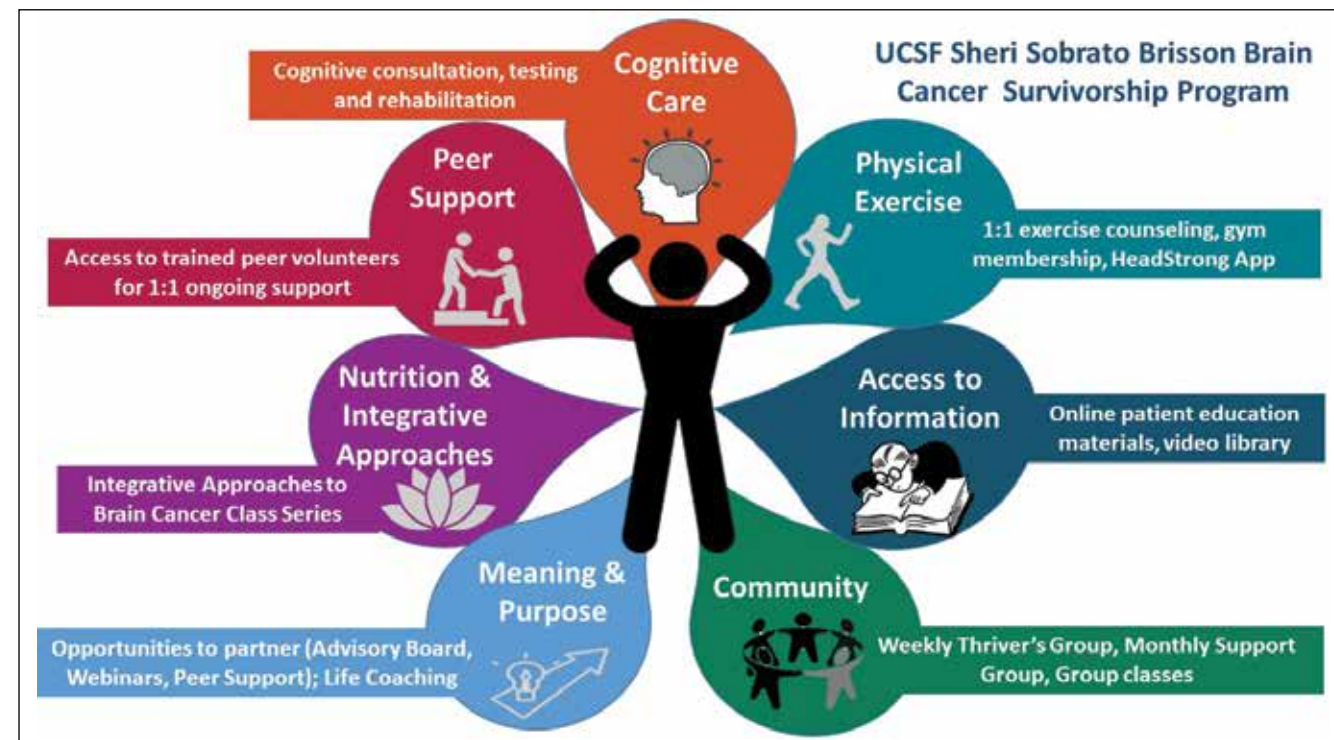


Figure 2 – UCSF Sheri Sobrato Brisson Brain Cancer Survivorship Program Pillars.

1. Cognitive Care – Understanding that cognitive challenges can impact one's physical, emotional, behavioral, and social well-being and that this also negatively affects a family system, the program prioritized the establishment of an embedded Cognitive Care Clinic. Services provided by this clinic include cognitive testing and evaluation, cognitive rehabilitation, and patient and family education. The focus is on strengths-based, goal-oriented, compensatory strategies that help survivors live their best lives and achieve their goals. Examples of these goals might include return to work or school, family communication, or "legacy projects" (activities for patients to help tell their story and meaning of their life for their friends and family). Whenever possible, caregivers are involved in the education and rehabilitation efforts.

2. Exercise - Evidence regarding the benefits of exercise in all areas of health promotion continues to accrue. In addition to benefits outlined for the general cancer survivor population, there are also areas that more specifically benefit the brain cancer population such as cognitive health, mobility, balance, and emotional regulation.

The *WorkOut for Wellness* (WoW) Program includes: (I) one-on-one exercise consultation to help patients develop and maintain an exercise plan in line with their goals and circumstances; (II) a complimentary gym membership at the local fitness center; and (III) access to the custom-built HeadStrong and HeadStrong Plus Apps containing video instructions for recommended exercises for patients with weakness, imbalance and mobility issues. These Apps also monitor progress and program adherence.

3. Access to Brain Cancer Survivor Specific Information - Survivors report being hesitant to do their own research because most existing survivorship information they find either speaks to curative disease management or offers alarming information on brain cancer and corresponding perspectives that are not representative of their outlook or situation. The team felt it important to create educational material that speaks directly to brain cancer survivors and the unique challenges they experience, such as cognitive functioning, fatigue, seizure management and workplace adjustments. Information is offered through (I) a

monthly *Living Well* webinar series [Table 1]; (II) one-page patient wellness handouts which will also be compiled into a survivorship manual; and (III) a monthly *Thrivers* e-newsletter. All these resources are available electronically on the survivorship web page to allow for general access at any time.

WEBINAR TOPIC
Balancing Work & Cancer
Exercising for Enhanced Wellness
Relationship Resilience through Brain Cancer
Coping with Cognitive Changes
The Ketogenic Diet
COVID 19 Special Issue
Coping with Fatigue
Coping with Fear and Anxiety
Seizure Management
Healing Power of Expressive Arts
Cannabis
Balancing Work & Brain Cancer
Lasting Legacies
Digging Deep: A Conversation with Sheri Sobrato Brisson
Getting a Better Night's Sleep
Thriving as a Young Adult with Brain Cancer
Psilocybin (Magic Mushrooms) for Cancer-Related Distress
Neuroplasticity & the Human Brain

Table 1: UCSF Living Well After Brain Cancer Webinar Series Topics

4. Social Support and Community - The many visible and invisible changes that often result from this disease can lead to increased isolation. Thus, the program emphasizes the importance of creating connections among survivors. The weekly Thriver's Group, monthly Support Group, *After the Show* live webinar component, and education-based group classes all offer a safe space for these connections to form and grow. Having these offerings on a virtual forum has increased access and participation and addresses the barriers of travel and time commitment for in-person events.

5. Meaning and Purpose - Many survivors are unable to maintain their prior employment or social roles because of their limitations, but still have a desire to contribute to society in a meaningful way. Another important aspect of the program is providing opportunities for survivors to contribute and make meaning out of their disease. Opportunities to contribute include:

serving on the survivorship advisory board, volunteering in the peer support program, and providing a patient voice as a panelist at a webinar. The program also directly helps survivors create a meaningful life after brain cancer through coaching sessions (part of the Thrivers' meetings) and through the goal-setting focus of the Cognitive Care Clinic.

6. Nutrition and Integrative Approaches - Nutrition is a vital component of one's well-being and choosing what one eats is also a way to feel more empowered. The program offers a bi-annual, three-part series of group classes in nutrition and integrative approaches to brain cancer, facilitated by an integrative oncologist. Patients with any kind of brain cancer and at any time during their cancer journey are welcome to participate and they also benefit from individual consultation with an integrative oncologist and a goal-setting coaching session by a wellness coach at every class.

7. Peer and Emotional Support - Survivors often express that it takes someone who has brain cancer to truly understand what it is like to live with this disease. The Neuro-Oncology Survivors' Peer Support Program matches survivors with trained peer volunteers to provide phone-based emotional support at any point in the disease process. Peer volunteers are trained to listen with empathy and let those seeking support know that they are understood and not alone. It is a powerful program that provides an invaluable service. Though general cancer peer support programs exist, the team recognized the value of an in-house customized version that would (I) allow volunteers a space to support each other immediately after the training; (II) allow staff to monitor the changing conditions of the survivors so direct assessments about their capacity to provide support can be made; and (III) allow volunteers a space to continue to learn and practice the listening and support skills with one another,

thereby getting benefit themselves and deepening their community connection. In addition to the emotional support provided by trained peers, the team also regularly refers patients and caregivers to psycho-oncology, social work and spiritual care services within the UCSF Cancer Center, as well as help them find mental health support and resources in their community.

Integration efforts with a comprehensive supportive care program

While most would agree that survivorship care is important, there are many challenges to integrating this into standard of care. A multidisciplinary team approach is critical to meet the complex survivorship needs of patients. With no uniform disease pathway, standardizing the timing to introduce survivorship services is a challenge.

Originally, the team's vision was to create a multidisciplinary survivorship clinic where survivors would have same-day, same-clinic access to various specialists. Although this model seemed promising, there were several organizational and logistical challenges such as coordinating the multiple disciplines, allocating clinic space, and creating a financial model for reimbursement. This approach also limited patient access to valuable resources outside the scope of the planned clinic.

Because of these barriers, the survivorship resources were intentionally made available to all patients at any time during their illness, while simultaneously allowing the clinical team to refer appropriate patients for specialized support services provided by the program. The team continues to work to better identify clinically relevant timepoints to introduce personalized survivorship care. In addition, the team is exploring a model to better assess the ongoing needs of survivors and measure outcomes and benefit.

To help facilitate communication between health care providers and remove barriers to care, the team continues to use virtual platforms such as shared electronic medical records and web-based conferences. In collaboration with the other supportive care programs (UCSF Gordon Murray Caregiver Program, social work, and palliative care) and to add support to the clinical care of patients, the survivorship team attends a weekly virtual interdisciplinary meeting focused on

discussing and addressing supportive care needs of patients actively seen at UCSF [Figure 3]. (<https://braintumorcenter.ucsf.edu/supportive-care>). These interdisciplinary meetings have brought further attention to survivorship issues, which in turn have created opportunities to better identify and address needs that may otherwise go undetected.

Conclusion and future directions

Cancer survivorship continues to be a growing need in the field of neuro-oncology. While there remains an urgent demand for the evaluation of novel treatments to extend survival, patients and caregivers need help "here and now" as they navigate the challenges and complexities of the disease journey. In a relatively short period of time, the UCSF Sheri Sobrato Brisson Brain Cancer Survivorship Program has addressed survivorship care by developing multiple pillars of support. Feedback from patients, caregivers, and health care providers indicates great enthusiasm for this type of survivorship care. The program has been critical in identifying and assessing survivorship needs for patients and has created sustainable pathways for ongoing support. These include exploring opportunities for reimbursement for billable services such as neuropsychological and neurocognitive care, palliative care, and integrative oncology referrals.

Many lessons can be learned from the survivorship program development and implementation. First, the needs of patients change throughout the disease journey necessitating ongoing assessments, and multiple access points. Survivorship care must be individualized, intentional and proactive, and keep the patient's family support system in mind. How to best operationalize these important factors is an ongoing area of work for the team. Continuing to leverage technology is critical in augmenting collaboration, extending program impact, and improving patient access. Lastly, seeking local and national partnerships with others with similar survivorship interests is key to measure outcomes, assess benefit, and pursue research efforts to improve survivorship resources and support for brain cancer patients. ■

Acknowledgments

The authors would like to first acknowledge and gratefully thank their patients for being a constant source of inspiration. Their perspectives have been invaluable in shaping the brain cancer survivorship program. In addition, they would like to thank the UCSF Sheri Sobrato Brisson Survivorship Program; Gordon Murray Caregiver Program; Brain Tumor Center; Christine Capurro Sand Brain Tumor Fund; and the Helen Diller Comprehensive Cancer Center for their generous support and partnership. Without this, the brain cancer survivorship program would not have been possible.

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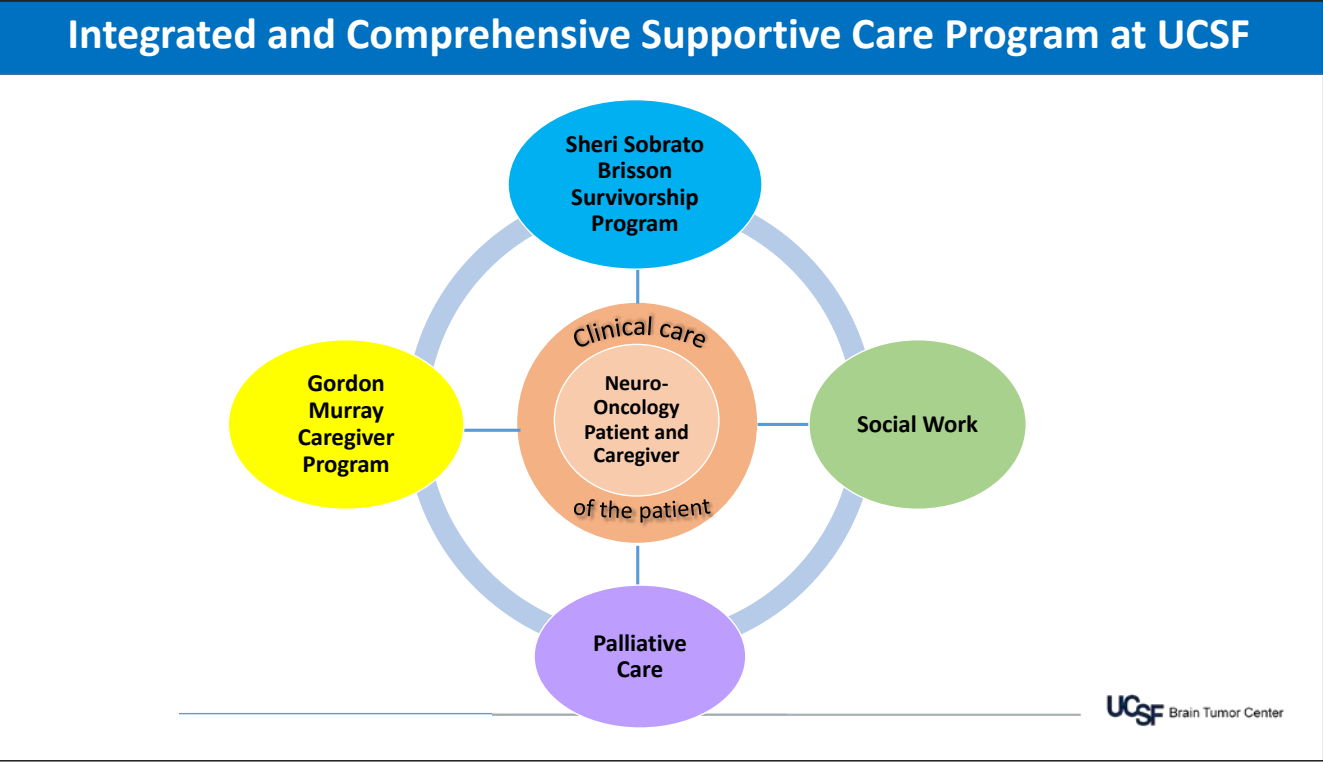


Figure 3 - Integrated and Comprehensive Supportive Care Program at UCSF. The Sheri Sobrato Brisson Brain Cancer Survivorship Program is one element of the comprehensive neuro-oncology supportive care program at UCSF. The supportive care program provides an extra layer of support to neuro-oncology patients and their caregivers. This additional support along with the care delivered at UCSF, helps patients better cope with their disease, and optimizes their quality of life. For more information, please visit <https://braintumorcenter.ucsf.edu/supportive-care>.

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Engaging the patient community in publications: the WECAN publications training course for patient advocates

Jan Geissler, Chair
Workgroup of European Cancer Patient Advocacy Networks (WECAN)

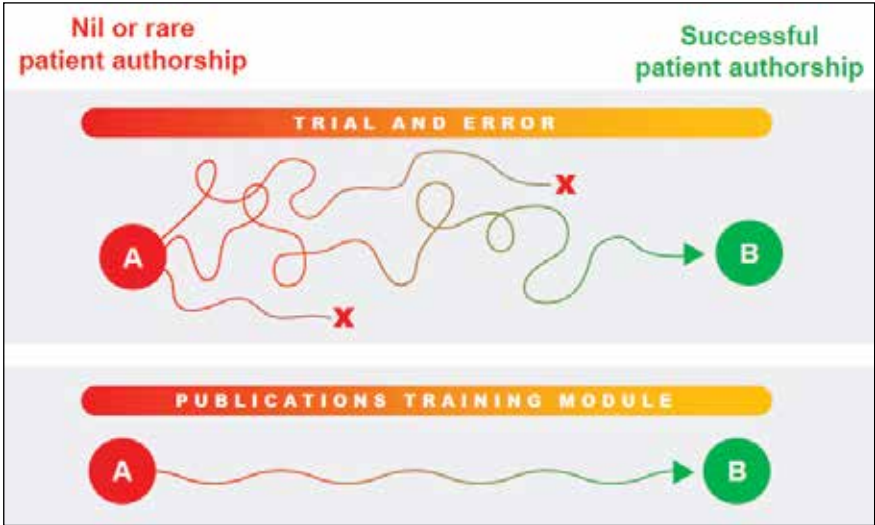


On June 21st, 2021, the Workgroup of European Cancer Patient Advocacy Networks (WECAN) in collaboration with Envision Pharma Group launched the world's first publication course of its kind – the Patients in Publications Training Course. Created by patient advocates and publication professionals, the open-access training course aims to teach patient advocates how to publish research as an author or co-author in peer-reviewed journals.

Patient involvement in publications

Patient organizations are engaging as partners in research projects and are also increasingly generating their own data. To make sure meaningful patient evidence is known and has an impact on researchers and policymakers, patient advocates are authoring or co-authoring articles in scientific journals and other publications. However, they often do not have the expertise on how to publish their research and survey data, and how to engage with publishers.

One of WECAN's core objectives is to grow the skills of patient advocates. To empower the patient community in planning, authoring and disseminating publications on patient-led or patient-partnered research, WECAN collaborated with medical communications specialists, Envision Pharma Group. Publication professionals have expertise in ethical and effective publication practices and patients and patient advocates are in the best



The efficient pathway to patient authorship

position to express what patients want and need. The objective was to co-create the world's first, open-access, publications training course with and for patient advocates who plan to publish their own research, or who have been invited to be co-authors or peer-reviewers of journal articles.

Why publish?

Publications from patient advocates are expected to increase, especially if patient advocates can access training on how to plan, generate, share and evaluate their publications. In order to help ensure that healthcare focuses on the true needs of patients and their communities, patient advocates should generate robust evidence and publish it.

Patient advocates who publish their research could enhance:

- **Patient care** – publications can help share peer-reviewed evidence from patient-relevant, patient-prioritized research (to reach healthcare professionals where they access information)
- **Patient advocacy** – publications can raise awareness about patients' needs and the value of patients as research partners (e.g., use publications to inform and work with researchers, regulators, payers, policymakers, research funders)
- **Organization's reputation** – publications can help increase credibility and raise awareness of patient advocacy groups/organizations

Successful collaboration between patient advocates and publication professionals

Over the past few years, WECAN and Envision Pharma Group collaborated to



2. WECAN Academy. <https://wecanadvocate.eu/academy/>. Accessed March 23, 2021.
5. Arnstein, et al. Patient involvement in preparing health research peer-reviewed publications or results summaries: a systematic review and evidence-based recommendations. Res InvolvEngagem. 2020;6:34

Above, illustration from a poster presented at the 17th Annual meeting of the International Society for Medical Publication Professionals on April 12-14 2021. The poster was created in collaboration with Karen L. Woolley, Jan Geissler, Tamás Bereczky, Amanda Boughey, Zack Pemberton-Whiteley, Thomas Gegeny, and Dawn Lobban.

develop the training course. Using a stepwise process (see above poster illustration from International Society for Medical Publication Professionals on April 12-14 2021) for developing the course, WECAN and Envision Pharma Group first created a core team. The core team consisted of patient advocates Jan Geissler (Patvocates and WECAN Chair), Zack Pemberton-Whiteley (WECAN member, Acute Leukemia Advocates Network) and Tamás Bereczky (Patvocates) and publication professionals Dawn Lobban, Professor Karen Woolley and Amanda Boughey from Envision Pharma Group and project managers.

After establishing the core team, WECAN patient advocates performed a needs

assessment. The assessment clarified whether a publications training course was needed by both patient advocates and the pharmaceutical industry and that the course would become an integral part of the WECAN Academy Knowledge Base and Evidence-Based Advocacy program. A systematic review (Arnstein et al., Patient involvement in preparing health research peer-reviewed publications or results summaries: a systematic review and evidence-based recommendations. Res InvolvEngagem. 2020;6:34) on patient involvement in publications and interviews with pharmaceutical companies confirmed the need for the training.

"Patients want to make their voices heard, sharing their perspectives of the lived disease and what's really important to them. One way of doing this is to disseminate their own research and data as authors and co-authors. But how do patients do this in the most professional way? How do they understand the peer review process, grapple with the key stages in the publication pathway and other challenges of publishing research? The Patients in Publications online course addresses all of these questions and more in an engaging, clear and compelling way."

Kathy Oliver, Patient Editorial Board, WECAN and Chair/Co-Director, International Brain Tumour Alliance (IBTA)

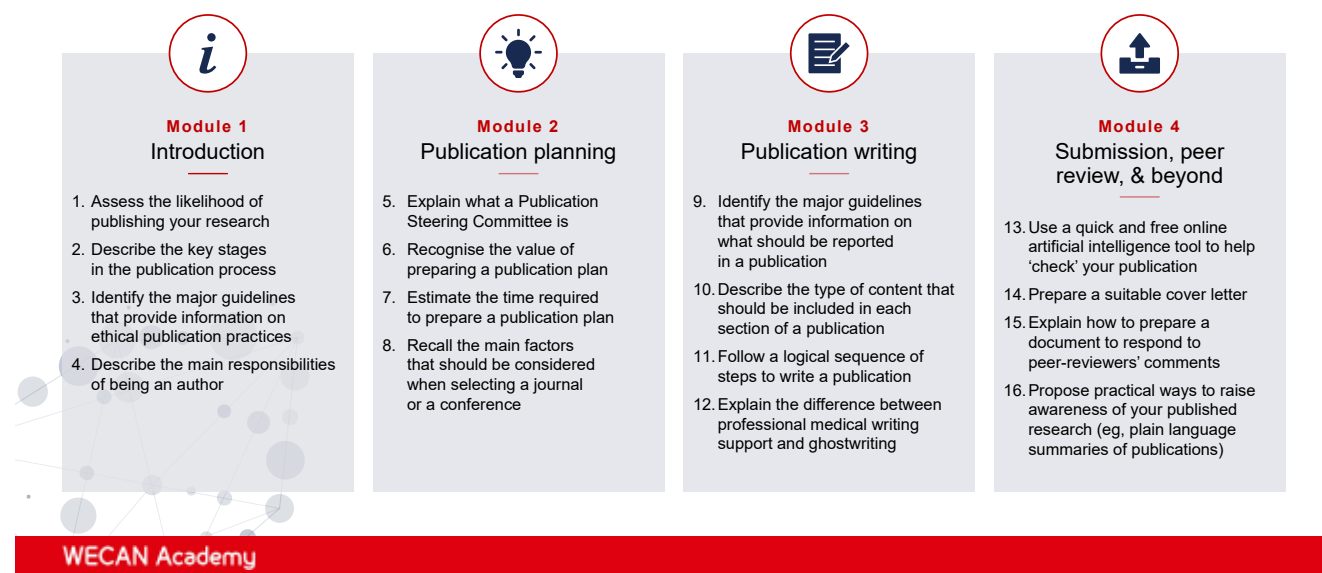
Next came funding. Since WECAN is not a legal entity, but an informal network of 23 pan-European cancer patient organizations, funding for the course was administered by the European Patients' Academy on Therapeutic Innovation (EUPATI) Germany and was obtained from industry and non-industry funders (Amgen, Bayer, IPSEN, Pfizer, Novartis, Roche and EUPATI). The funders had no role in course development.

In order to gain consensus on course objectives and scope, an independent Patient Editorial Board was established. The Patient Editorial Board generated content, such as case studies for the course, and reviewed the detailed course

continued ➤

Training course – 4 modules

After completing each module, patient advocates should be able to:



Overview of the Patients in Publications training course

outlines and content that Envision Pharma Group developed. It was important to have representation of various cancer patient organizations. Comprising the Patient Editorial Board were Ananda Plate (Myeloma Patients Europe), Gilliosa Spurrier (Melanoma Patient Network Europe), Judith Taylor (Thyroid Cancer Alliance), Kathy Oliver (International Brain Tumour Alliance), Katie Rizvi (Youth Cancer Europe), Tamás Bereczky (Patvocates), Teodora Kolarova (International Neuroendocrine Cancer Alliance), and Werner Zinkand (Myeloproliferative Neoplasms Advocates Network) who volunteered their time to co-create the training course.

The result

A successful collaboration between patient advocates and publication professionals enabled the "Patients in Publications Training Course" to be launched in June 2021 on the WE CAN website. The training course blends learning styles through four self-learning modules that take about one hour each to complete. Each module includes case studies, reflective exercises, and is accessible to all with no restrictions.

- The first module provides an overview of the key stages in the publication process

and describes major guidelines on ethical publication practices. It also describes the main responsibilities of being an author or co-author of publications.

- The second module explains what a publication steering committee is, outlines the value of a publication plan and gives guidance on how to select an appropriate conference or journal.
- The third module provides guidance on writing the content of a publication, so the key elements of a scientific article, the logical sequence of steps to write a publication, and how to work with professional medical writers.
- The fourth module covers how to submit an article to a journal, practical advice on responding to peer-review comments, and how to create awareness once an article has been published.

After taking this four-module training course, patient advocates will have the capabilities to engage across the whole authoring and publication process of patient-relevant evidence. To make them available as broadly as possible, the

"Patient advocates are increasingly involved in research and publishing. Understanding the scientific publishing process is key to preparing an article for publication with the highest chance of success and these training modules provide an excellent basis for navigating each stage and achieving a successful publication."

Judith Taylor, Patient Editorial Board, WE CAN and Co-Director and Secretary, Thyroid Cancer Alliance (TCA)

training modules are provided at no cost to participants under the Creative Commons License (CC BY 4.0). This generous license means that you are free to share and adapt the material for any purpose. The course can be found at <https://wecanadvocate.eu/patients-in-publications/>. ■

PATIENTS IN PUBLICATIONS

Open Access Training Course



CO-CREATED BY WE CAN AND ENVISION PHARMA GROUP

WHO IS IT FOR?

For patient advocates who plan to publish their own research, or who have been invited to be co-authors or peer-reviewers of journal articles.

WHAT DOES IT COVER?

This course will help you to assess, plan, and publish research in a peer-reviewed journal. You will explore case studies and learn tips from experts.

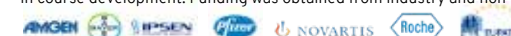
ABOUT THE COURSE

- Four one hour modules
- Self-paced
- Open access



Access the course now at wecanadvocate.eu/patients-in-publications/

Funding for the course was administered by EUPATI Germany. The funders had no role in course development. Funding was obtained from industry and non-industry funders:



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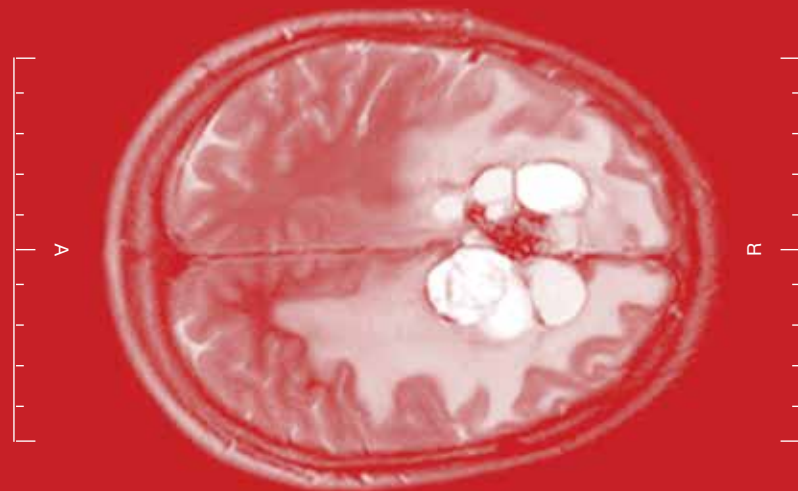


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www. Stichting
Hersentumoren.nl

Guided intervention for brain tumour patients reduces their stress

Noa Faaij

The Netherlands

My name is Noa Faaij, I'm 16 years old and I live in the Netherlands. In my last year of high school, I was asked to do a graduation assignment and decided to research brain tumour patients and the stress which they experience. I chose this subject because of my own experiences with my father, who has a malignant brain tumour, and who easily gets stressed from the simplest of things. I wanted to find out what caused that stress and, more importantly, what can be done to intervene. With my research on this topic, I hope to help realise a better quality of life for brain tumour patients through stress reduction.

I was three years old when my father had a major epileptic seizure in the middle of the night. As a toddler I stood at my father's side with my toy doctor's suitcase to assist the paramedics. Shortly afterwards, my father was diagnosed with a grade 2 brain tumour that has since dominated my father's and my family's life.

After an awake craniotomy in 2014 to remove large parts of his tumour, my father suffered brain damage and the need for family care intensified for him. Ever since I could remember, I always wanted to become a doctor. I hadn't yet decided what discipline of medicine I would like to practice, when I was invited, at 14 years old, to join a neurosurgeon for a day. I attended two brain tumour operations and became fascinated with neurology. Afterwards, I knew that I wanted to become a neurosurgeon.

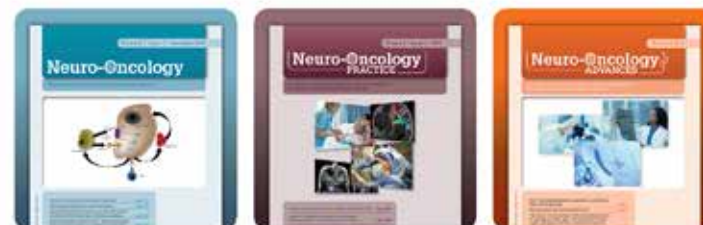
In the Netherlands, all high school students must submit a research paper before taking their final exams. The research paper is meant to be a culmination of their secondary school academic careers and meant to show everyone what they have learned in the years they attended school. I naturally wanted to use my paper to write something about neurology. I proposed to the STOPbraintumors.org foundation and subsequently to the University Medical



This is me when I was 10 years old, helping the GP remove my father's sutures, 14 days after his brain tumour surgery.



SNO
Society for NeuroOncology



The Society for Neuro-Oncology exists to advance multi-disciplinary brain tumor research, education, and collaboration to drive discovery and improve patient care.

For more information, visit:

www.soc-neuro-onc.org



Shaving my father's head. I'm on the far right

Centre in Utrecht, the Netherlands, a study concerning the stress which brain tumour patients experience during their treatment. This offer was met with great enthusiasm from both organizations.

My research project on stress and primary brain tumours

After preliminary investigations, I was surprised to find little research done concerning the relationship between stress and primary brain tumours, especially in the Netherlands. So I posed the following question for my high school paper: "Do brain tumour patients experience stress during their treatment and does giving intervention resources help to reduce this stress?"

Over the course of eight weeks, I recruited participants for my project and employed a multitude of surveys and exercises to obtain their responses on my research question. My first survey went out to anyone with a relationship to a brain tumour; this included patients and their parents, partners and children. One hundred and eighty-one people completed my questionnaire which gave me an insight into their lives and their brain tumour-related stress. Eighty patients were willing to participate in my eight-week long project.

Based on my preliminary research, I compiled a list of intervention tools, which previous research had highlighted as being

most effective as a stress reducer. These fell into three categories: music, meditation and sports.

Then I divided the participants into two groups: the research group (G1), to whom I handed out these intervention resources, and the control group (G2).

The research group (G1) was instructed to spend a minimum of 15 minutes each day, during the eight weeks, trying at least one of the three categories of resources provided. The control group (G2) was given free rein to de-stress in any way they wished.

Every Sunday for eight weeks, I sent surveys to both groups (G1 and G2) and asked them to rate their days and week in terms of stress. Furthermore, I asked what they had done to combat stress and whether they thought the interventions had helped.

The results of my brain tumour and stress study

Fifty percent of all the brain tumour patients surveyed in both groups indicated that they experienced high levels of brain tumour-related stress.

I also researched the most stressful brain tumour-related experiences that patients had. Three types of events, in particular, caught my attention. Forty-eight percent of the patients I surveyed rated their routine MRI scans to be the most stressful event [see Figure 1] and 46% of patients surveyed thought the event of diagnosis to be the most stressful. Forty-one percent of patients surveyed felt that experiencing new brain tumour growth was the most stressful.

I feel that the significant stress brought on by MRI scans is important because brain tumour patients generally have an MRI scan every three to six months to track their tumour growth. The data which I collected from my patient participants in my questionnaire shows that patients are more stressed out during an MRI scan than when they receive their diagnosis. I thought that if the amount of stress experienced by patients having MRIs every three to six months was regularly nearly as much stress as that caused by the day of diagnosis, then this was a very concerning revelation.

I then wondered whether brain tumour patients receive professional support to combat these high stress levels.

The data from my high school project indicated that 65% of brain tumour patients said that they are not provided with professional care and help for these matters. Furthermore, although patients shared their concerns with their general practitioner (GP) or treating specialist, a very small number of patients actually received help.

My findings were extremely interesting to me.

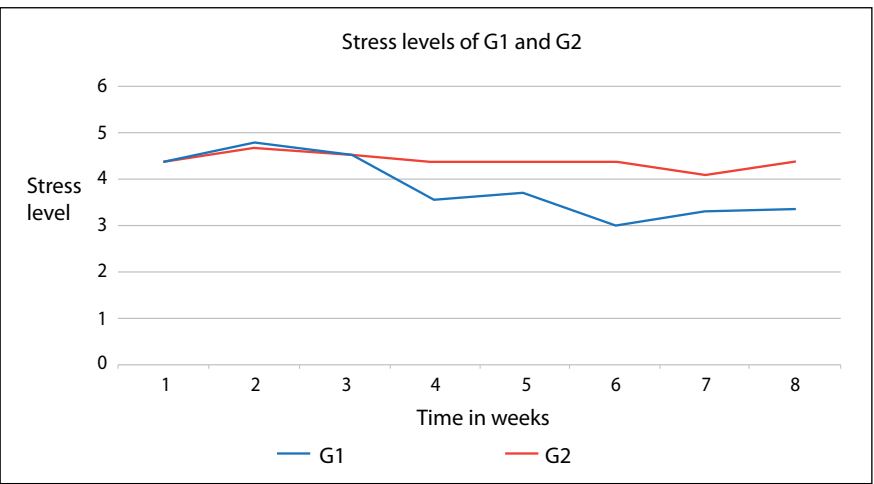
The control group (G2) destressed with normal, daily activities such as taking part in sports, walking their pets, watching TV, reading a book or listening to music, but not with the active goal of reducing their stress. Most of all, their life continued. Some in the control group slept more often or visited friends and family to talk about their illness.

However, in the research group (G1) in brain tumour patients who used structured intervention resources, their stress levels dropped. I measured a 33% reduction in stress levels in the research group (G1), a reduction already apparent shortly after the third week. In the research group (G1) – using active guidance and intervention methods – patients experienced significantly less stress in their lives than the control group. Additionally, a large part of the control group (G2) used interventions which fell within the three categories which the research group (G1) used: music, meditation and sports. Apparently, consciously dealing with stress – using only three interventions and external guidance – may give the brain tumour patient a clearer focus to reduce their stress.

A larger study in the future?

While the results of my research were fascinating to me, my research is far from perfect or complete. For example, I recruited a very small number of patients. Additionally, I didn't take the grade of the brain tumour into account during my research. So my conclusions are far from definitive. But I do hope that my study will be repeated with a larger patient group and be able to take account of grades of brain tumours. I also hope that a larger, more comprehensive study will prove my results to be valid.

Recently, I applied for the study of medicine at the University of Utrecht, in the Netherlands, a program with a limited number of places available. I really hope that I'm able to live my dream of becoming a neurosurgeon. ■



Average stress levels of groups G1 and G2 during the study



This is me, as I am now

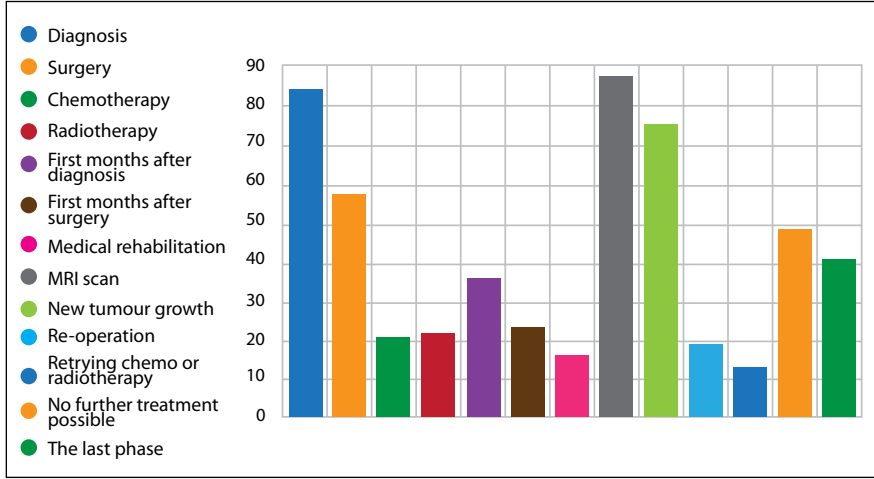


Figure 1. This is data from my research showing the most stressful situations according to the study participants

If you would like to read more about Noa's research, please email info@STOPhersentumoren.nl

In response to Noa's research, the STOPbraintumors.org foundation has issued an application call regarding the research question: "Does the stress brain tumour patients experience affect the longevity of their life?", with a research grant available of up to Euros 100,000. For more details about this research call, please contact: KHofstee@STOPhersentumoren.nl

TRK inhibitors for central nervous system tumors: new promising targeted therapies

Sébastien Perreault, MD, M.Sc., FRCPC, Director of the Pediatric Neurology Program
Department of Neurology, CHU Sainte-Justine, Montreal, Quebec, Canada

NTRK1 gene fusion was first described in colon cancer in 1982 and was followed by the Canadian discovery of the *ETV6-NTRK3* gene fusion in infantile fibrosarcoma in 1998. Under normal conditions in the body (aside from in cancer), *NTRK1*, *NTRK2*, and *NTRK3* genes play a role in multiple processes, including cell differentiation, pain, regulation of movement and memory. When these genes are fused with another gene partner (leading to what is called an *NTRK* gene fusion), the pathway loses its regulation and the uncontrolled signaling cascade can lead to the development of tumors.

Frequency of *NTRK* gene fusions

NTRK gene fusions have been identified in a variety of pediatric and adult tumors and are estimated to occur in up to 1% of all solid tumors. These fusions are frequent in specific rare cancers such as infantile fibrosarcoma (greater than 90%) and rare in common cancers such as lung cancers and breast cancers (less than 1%).

Importantly, *NTRK* gene fusions are also found in primary central nervous system (CNS) tumors. *NTRK* gene fusions occur in up to 2% of adult primary brain tumors while in the pediatric brain tumour population, *NTRK* gene fusions have been observed in up to 5.3% of high-grade gliomas and 2.5% of low-grade gliomas. Of note, high-grade gliomas with *NTRK* gene fusions can be found in up to 40% of infants (less than three years old).

Identifying *NTRK* gene fusions through testing

Given *NTRK* gene fusions are rare, the key challenge is to identify patients with this characteristic.

In specific cancers, *NTRK* gene fusions can be identified with fluorescence in-situ



Dr Sébastien Perreault, M.Sc., FRCPC of CHU Sainte-Justine in Montreal

hybridization (FISH) testing but for CNS tumors, next-generation sequencing (also called NGS), which analyzes DNA or RNA, needs to be performed. This is usually undertaken on a fresh frozen specimen of the tumor obtained at the time of the resection (surgery). Good coordination and collaboration with neurosurgeons

and neuropathologists are therefore essential to preserve the tumor and run the appropriate tests. (While “liquid biopsy” or sometimes-called cell-free DNA (cfDNA) may be an option for other solid tumors, it is not typically useful in primary CNS tumors due to the lack of circulating blood stream tumor DNA)

Treatment options for patients with *NTRK* gene fusions

Once the *NTRK* gene fusion is identified some patients will need to start systemic therapy depending on the extent of surgical resection, tumor type and treatment journey.

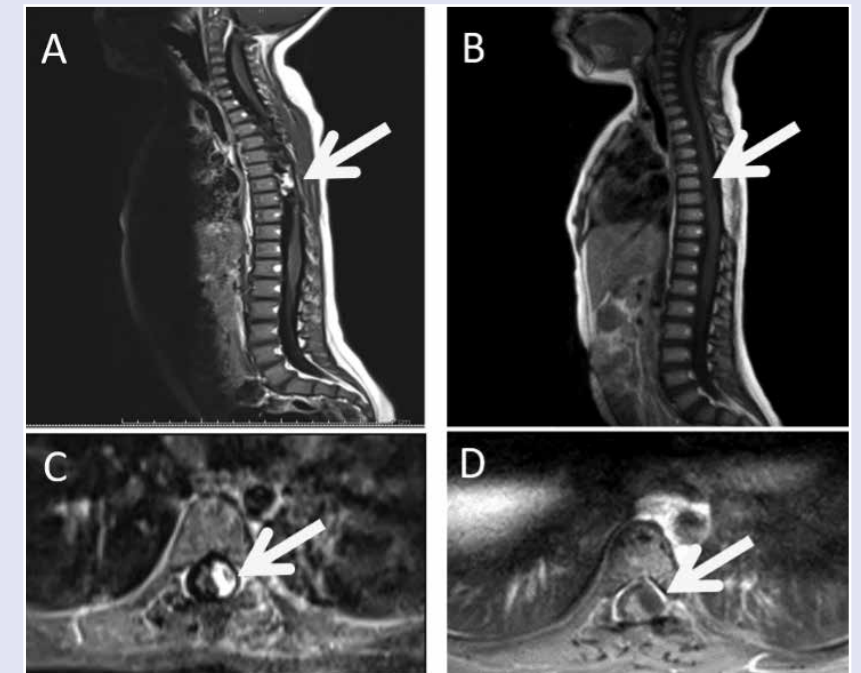
A subset of cancers are known to respond well to nonspecific systemic therapy such as chemotherapy but for some patients, available treatments are limited, inefficacious and highly toxic. In these settings, targeted therapies offer interesting new options with the preservation of a good quality of life.

Two agents are currently approved in several countries for treatment of *NTRK* fusion cancer: larotrectinib and entrectinib. Larotrectinib (approved for any aged patient) and entrectinib (approved for patients 12 years or older) were studied in so-called “tumor-agnostic” phase I and II trials called “basket trials”, meaning that patients could be enrolled in the study regardless of their tumor type if they had *NTRK* gene fusions.

In a pooled analysis of 206 evaluable patients presented at the American Society of Clinical Oncology (ASCO) conference in 2021, 75% of patients treated with larotrectinib presented a significant response to treatment (up to five years) and most patients did not show evidence of progression until after three years. Complete responses were reported in various types of adult and pediatric tumors, even in patients who were heavily pretreated and in palliative care. Importantly, larotrectinib was well tolerated in these patients and only 2% of patients needed to stop their treatment due to side effects.

A subset of patients with CNS tumors and *NTRK* gene fusions were treated in two clinical trials. I recently presented at ASCO 2021, a sub-analysis of primary CNS tumors. A total of 33 patients with CNS tumors received larotrectinib including a majority of glioma patients (82%) and most were high grade glioma (58%). A total 30% of patients presented a response (50% or more tumor shrinkage) including three patients with a complete disappearance of the tumor. An additional 20 patients had stable disease, 15 of those for more than 6 months. All responders were pediatric patients. Tumor shrinkage was rapid, and responses occurred in less than two months. Similar to patients with other solid tumors,

NTRK Pediatric patient case study



Pediatric patient diagnosed at four months with high grade glioma.

Patient was treated for 72 weeks with standard chemotherapy. He was hospitalized more than 20 times for chemotherapy infusions and complications related to treatment.

He had progression of the disease at three years and an *ETV6-NTRK3* fusion was identified using next generation sequencing. He was enrolled in a clinical trial (called SCOUT) and treated with larotrectinib. He had a complete response after two cycles (eight weeks) and has been on treatment for more than two years without evidence of disease. He has had no significant side effects.

Figures A and C show magnetic resonance images (MRI) with the tumor at baseline and figures B and D show a complete response after treatment with Larotrectinib. ■

treatment was well tolerated, and no patient discontinued treatment due to side effects.

Another drug used for *NTRK* gene fusion, entrectinib not only blocks the *NTRK* gene, but also ROS1, ALK, and JAK2 (known as a multi-kinase inhibitor). It was studied in several trials for patients with solid tumors. In a pooled analysis of 54 patients, the overall response was 57%. Side effects led to a reduction of dose in 32.4% of patients and discontinuation of treatment in 8.8%. As of July 1, 2019, five patients with *NTRK* fusion primary CNS tumors were treated with entrectinib in a clinical trial called STARTRK-NG and achieved an overall response rate of 80%.

Several studies are currently ongoing to continue to evaluate the efficacy and safety of TRK inhibitors for adult and pediatric patients with CNS tumors. Research consortiums include COG (Children Oncology Group), CONNECT (Collaborative Network for NEuro-oncology Clinical Trials) and pharmaceutical industry studies.

Drug resistance is an inevitable problem in targeted therapy treatment, including with TRK inhibitors. If a TRK inhibitor stops working, it is important to test the tumor again to identify any known ‘resistance mutations’, which can emerge in the tumor as the cancer learns to adapt and become less affected by the treatment.

continued ►

New TRK inhibitors, such as repotrectinib and second generation TRK inhibitors, such as selitrectinib, have been designed to overcome resistance and are currently in early clinical phases of investigation.

Conclusion

In conclusion, *NTRK* gene fusions are rare in CNS tumors but are enriched in specific subsets of patients such as high-grade glioma in infants.

All CNS cancer patients should be tested for the presence of an *NTRK* gene fusion when no other characteristic mutations are found since therapeutic approaches can be drastically changed.

TRK inhibitors demonstrate impressive and rapid responses. More mature data will help in selecting one TRK inhibitor over another in respect to efficacy and safety. ■

Keep up to date...



The International Brain Tumour Alliance maintains a constantly-updated list of major regional, national and international neuro-oncology and cancer conferences and other meetings relevant to brain tumours.

These conferences and meetings include those organised by brain tumour patient organisations, medical societies and others.

Educational webinars and virtual events are also listed on the IBTA website calendar.

If you are organising or are aware of a forthcoming patient/brain tumour advocacy event or a scientific conference, whether it is virtual or in-person, taking place in 2021 or 2022, please let us know by emailing kathy@theibta.org

You can view the IBTA calendar of events here: <https://theibta.org/events-and-conferences/> ■

NTRKers - never alone: testing, knowledge, support



Susan Spinosa, founder of NTRKers



The NTRKers is a global, non-profit patient organization, which welcomes and unites patients, parents, families, and care partners impacted by NTRK gene fusion cancer.

Founded by patient survivors and care partners, their goal is for every adult and child with an NTRK gene fusion cancer to have the best chance of living life to the fullest – and that means better access to testing, treatment, and

research. NTRKers collaborates closely with multiple cancer groups and the medical community to achieve these efforts.

Susan Spinosa, patient survivor and founder of NTRKers, said: “We live with different tumor types but our cancers are driven by the same, rare genomic alteration called an ‘NTRK gene fusion’. The only way to detect such cancer drivers, and match patients with potential targeted treatment options, is through biomarker tumor testing. This can be a game changer for patients like us. Our hope is that all appropriate cancer patients can access biomarker tumor testing – whatever their underlying gene fusion or mutation.

“Our group is driven by the belief that no one should face cancer alone. We know from our own personal experiences that it can be difficult to find appropriate support when facing cancer that is driven by a rare mutation or genomic alteration, such as NTRK. It can be a very lonely, stressful journey. We don’t always know what to ask and where to turn for help. Parents of children with cancer have a particularly challenging time understanding what their child is going through and the options going forward.

“That is where we hope the NTRKers come in. We are there to support patients of all ages and their care partners.

“I invite you to explore our website (www.NTRKers.org) and follow the NTRKers on Twitter (@NTRKers) and Instagram ([ntrkers](https://www.instagram.com/ntrkers)) or get in touch by emailing info@ntrkers.org. Check out our stories, webinars, blogs and resources. If you or a loved one is diagnosed with an NTRK gene fusion cancer, we welcome you to join our closed Facebook group (NTRK Support Group) where you can connect with others, share experiences and learn from each other. You can also find an NTRK expert on our website. We are lucky to be supported by an excellent voluntary Medical Advisory Committee (<https://ntrkers.org/resources/ntrk-experts/>) of leading NTRK researchers from around the world.

Do get in touch. We would love to hear from you!” ■

A Day in the Life of a Brain Tumor Patient’s Nurse Navigator

Kelly Glover, BSN, RN - Neuro-Oncology Nurse Navigator at Brain Tumor Network United States

Kelly Glover, BSN, RN is a neuro-oncology nurse navigator at Brain Tumor Network, a national non-profit organization based in Ponte Vedra Beach, Florida, USA. Brain Tumor Network is committed to providing free, personalized navigation services and information about treatment related options to individuals and families across the United States whose lives have been impacted by a brain tumor.



06:02

Eyes open. It’s never too far from my mind that someone, somewhere, is going to receive a cancer diagnosis today. They will be bombarded with more information than they can feasibly process right now and handed off to a complex healthcare system that is not set up to be easily navigated, while still dealing with the shock and fear brought about by their diagnosis. Chances are, they will not know where to turn for help. I know this because, not too long ago, I was the patient receiving a cancer diagnosis. My journey as a cancer survivor inspired me to help others along the same journey. It’s the reason I left the business world to pursue a career in nursing, the reason I joined Brain Tumor Network (BTN), and the passion that propels me out of bed each morning.

08:24

Organization is key. In my role at BTN, I have an average caseload of about 40 brain tumor patients. BTN is a full-service organization: we are not part of a larger health system; therefore, we are able to provide a large variation of free, personalized and unbiased brain tumor navigation services including medical records review, attending virtual visits with patients and physicians, locating second opinions, and enrolling in clinical trials. I spend the first few minutes of each day reviewing and organizing my daily schedule.



Kelly Glover, a nurse navigator at the Brain Tumor Network

08:42

Flexibility is also key. Today, like many days, I received a phone call from the caregiver of a patient who was admitted to the Intensive Care Unit at their local hospital overnight. The caregiver had questions about whether this hospitalization would disqualify their loved one from participating in an upcoming clinical trial and needed a few minutes of reassurance and encouragement.

09:00

A majority of my day will be spent checking in via email and phone calls with new and existing patients and caregivers,

continued ►



Brain Tumor Network Navigation Review. Left to right: Jenna Tozzi, Nurse navigator; Kendra Paapbo, Manager of Navigation; Kristie Naines, Executive Director and Laura Hynes, Director of Operations

ensuring that their needs are met, and evaluating them for additional services, which, often times, include psychosocial support. Another thing that makes BTN unique is our co-navigation model, in which each patient is assigned both a nurse navigator and a social work navigator. Our team works hand-in-hand to meet the complex needs of our patients, and I regularly check in with my colleagues to assess each patient's overall status.

11:12

This will be the first of many calls to clinical trial coordinators today. We are extremely fortunate at BTN to have what many in our industry consider to be the "gold standard" in clinical trial navigation services. Utilizing our proprietary clinical trial search tool, we assist patients in locating clinical trials based on the unique facets and factors of their disease, and once located, help to enroll them as well. At BTN, we are fortunate to have built relationships and respect within the brain tumor community, and this makes our interactions with clinical trial coordinators more efficient.

11:52

You can't pour from an empty cup. I always try to make sure that I step away for a few minutes during the day to have a quick meal and practice self-care. For me, this can be as easy as stepping outside for a few moments of fresh air and blue skies, and then I'm right back to my next patient.

12:45

I receive an email from one of our Health Information Assistants indicating that a new patient's medical records have been uploaded into our database. This patient's diagnosis is complex and advanced. In total, there are over a thousand pages included in the medical record, but over the years, I have developed expertise in condensing this information into useful pieces to help the patient find the services they need. This particular patient has come to BTN because they are interested in receiving a second opinion regarding their treatment. This is another area in which BTN's long-standing relationships are important: I locate the Center of Excellence with the nation's top expert on this patient's tumor type, and the receptionist knows me by name. The patient is able to get an appointment for the following week.

13:15

I think the most difficult aspect of navigating brain tumor patients is coping with loss. Today, I am contacting the family of a patient who passed away a few months ago to check in. During the call, the patient's sister tells me that until her brother came to BTN, he wasn't getting the care he deserved, and that they will be forever grateful. In these moments, I am so thankful that my journey led me here.

14:30

It's early afternoon, and I've just completed a follow-up call with a clinical trial coordinator as I help a patient enroll in a

groundbreaking study. As I complete my notes, I receive a call from another patient with a question about wound care. Quickly switching gears, I offer information about nutritional changes that may help alleviate their post-chemotherapy side-effects.

16:15

One of my favorite things about working at BTN is the multidisciplinary collaboration. We have just completed a zoom call with our team of nurse and social work navigators to discuss new clinical trials. We do this regularly, and navigators are always working together behind the scenes to help our patients get the best and most comprehensive and timely care possible.

17:00

While I'm always available to my patients in an emergency, it's time for me to sign off and spend time with my family.

If my journey as a cancer survivor and brain tumor nurse navigator has taught me one thing, it is this: appreciate the little things. Appreciate the family dinners, evening walks, beautiful sunrises and sunsets, and the quiet moments in between. I appreciate the opportunity I have every day to make someone's cancer journey a little better, and for me, that's not a little thing - it's everything. ■



A Brain Tumor Network (BTN) nurse navigator working to secure a second opinion for a patient

For more information about the Brain Tumor Network, you can visit their website at <https://www.braintumornetwork.org/>

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OCTOBER 23, 2021

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If you are a patient, a caregiver, or a friend call: **(619) 515-9908** or email: **info@sdbtf.org**

www.sdbtf.org



Fondo Alicia Pueyo
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Fighting Diffuse Intrinsic Pontine Gliomas



Funding research
on brainstem gliomas



Supporting Families
fighting this terrible disease



Promoting
international collaboration to find a cure

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New clinical trial with autologous dendritic cells pulsed with tumoral cell-lines lysate
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Collaborations needed to fund this project
Those interested, contact ggarciaca@sjdhospitalbarcelona.org

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Brainstem gliomas of childhood - a lifetime of lessons for the future

David A Walker B Med Sci BM BS FRCP FRCPCH Emeritus Professor of Paediatric Oncology University of Nottingham, Co-PI Children's Brain Tumour Drug Delivery Consortium (www.cbtdc.org).



The Anticancer Fund (<https://www.anticancerfund.org>) is a Belgian non-profit organisation with an international scope. They promote, finance and/or coordinate clinical trials and offer non-judgmental and evidence-based information about cancer treatments to patients. For DIPG Awareness Day this year, 17 May 2021, they asked Professor David Walker to write a blog on their website. We are grateful to the Anticancer Fund for allowing us to reprint this blog by Professor Walker.



Professor David A Walker

A career view

As a recently retired paediatric neuro-oncologist I can look back over 40 years of experiences with children and families, facing the devastating impact of this group of diseases.

On the one hand we could focus on Diffuse Intrinsic Pontine Glioma (DIPG) and its frighteningly low survival rates, the devastating progressive neurological damage and the lack of progress despite extensive trials of radiotherapy, chemotherapy and translational research. On the other hand, we could list all that we have learnt and put it into perspective for future researchers so that the experiences of the past, inform the developments of the future. I prefer the latter approach.

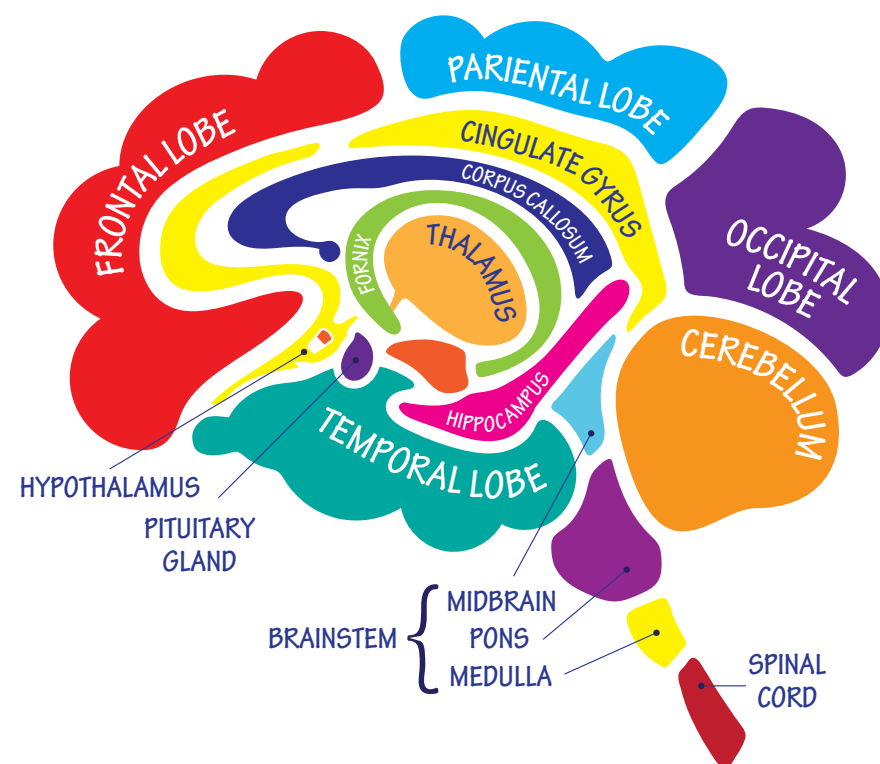
Anatomy and tumour pathology matter

The brainstem extends from the thalamus in the middle of the brain to the top of the spinal cord. The pons is a nerve bridge at approximately the midpoint of this span. Tumours above the pons are either called "thalamic" or "midbrain" tumours. Those involving the pons are referred to as "pontine" and those arising in the brainstem below the pons are called "medullary". When the tumours are astrocytic type and in these locations they constitute "Midline Gliomas". Their imaging appearances vary; some are "intrinsic", growing within the brainstem structures; some grow out from the

brainstem and referred to as "exophytic". Some are "diffuse", merging without boundaries into brain structures; others are "focal", forming nodules or cysts.

Pathologically some are considered benign / grade 1, typically characterised as pilocytic histology with a variety of BRAF mutations, some of which are targetable by drugs. They grow slowly and spontaneously stop their growth when adolescence ends. Others are malignant / high grade, they continue to grow, invade and spread within the brainstem and the rest of the central nervous system causing progressive disability and almost inevitable death. An exciting recent discovery has

continued ►



linked the h3K27M histone mutation to a new combined anatomical category of malignant diffuse midline glioma.

Taken together these descriptive characteristics matter as they determine the surgical approaches that are possible to sample tumour tissue, drain cysts, remove tumour nodules or exophytic growths, infuse drugs to tumour within or on the surface of the brain or direct ultrasound to disrupt the blood brain barrier to enhance drug penetration. The grading of “benign” versus “malignant” and “molecular” typing helps predict tumour behaviour and is being used to select drugs and delivery techniques to target tumour growth mechanisms in different anatomical locations in clinical trials.

Currently effective therapies

As a clinician, the most important lesson I have learnt is that the tumours in this location threaten life and disability by interfering with the brainstem’s life-preserving functions of breathing, swallowing, mobility and cardiac function. For focal and exophytic tumours, surgical resection is often possible and can be dramatic in its impact on symptoms, especially in grade 1 tumours. Diffuse tumours are not surgically removable and

are considered malignant and are treated with radiotherapy, to which they are only partially sensitive. Radiotherapy in the Diffuse Midline Glioma is considered temporarily palliative and can be used more than once, but with increasing risk of irreversible local brainstem damage with each treatment. Steroids remain almost the only effective drug treatment to control symptoms, which they do, by reducing the effects of brain swelling on brainstem function. Their continuous use in children, however, is associated with disturbing side effects on appetite, endocrine function, leading to weight gain, behavioural disturbance and can cause distressing disfigurement of appearance and reduced mobility due to muscle wasting. Steroid dosing strategies, if adopted, can be very effective in reducing these side effects.

Other anti-angiogenic drugs, such as bevacizumab, can preserve neurological function, with fewer side effects. Neither of these drugs treat the tumour itself. They do preserve brainstem function, which is, in itself, life-preserving and offers control of neurological deterioration, at a cost. Survival rates range from over 50% 5 year survival to less than 10% 5 year survival. The differences are related to

characteristics I have described. The best outcomes are for children amenable to tumour resection with low grade tumours and the poorest survival is for the diffuse intrinsic pontine glioma.

Targeting the tumour with novel drug and delivery strategies is now possible.

The stage is uniquely set for a new range of treatment trials in this group of diseases as the surgical and radiotherapy strategies are established and their effects understood. Cytotoxic drugs, given systemically and in combinations at maximised doses, have not to date produced any measurable benefit, perhaps because they do not penetrate the blood brain barrier (BBB). A new set of strategies are being applied, using anatomically and biologically targeted approaches to selecting drugs for their capacity to act on specific mechanisms and their capacity to penetrate or bypass the BBB by drug design or delivery techniques such as:

- drugs with lipid solubility characteristics
- convection enhanced drug delivery (CED),
- ultrasound blood brain barrier disruption (USS BBBD),
- intra-CSF delivery,
- intra-arterial therapy
- immunological targeting
- transmucosal delivery
- electric field therapy

These offer innovation of effect and greater certainty as to the drug / treatment’s delivery to the tumour and brain tissues, whilst minimising systemic doses and associated side effects. Creating a rationale for prioritisation of drugs / treatments in combination with a delivery system for such trials is an essential step to avoid wasteful repetition and illogical selection. Designing a total treatment programme, combining technical elements of therapy, and its delivery, with synergistic actions aimed at prolonging life and avoiding disability is a key objective.

International research cooperation poses challenges and offers great hope

Perhaps the greatest hope for the future lies in the international collaboration that now exists between translational

researchers to develop and test these new ideas. The pressure from distressed parents to try anything to save their child is a powerful motivation and an ethical challenge to all who work in the field. The impact of “hope” with any new treatment, raises expectations for distressed families, who feel that they have very limited time with their ill child and that anything is worth trying, at any expense. The clinical, scientific and ethical challenges in this rare condition of children means that:

- there are conflicts about prioritising which treatment to try next and in what combination;
- there is a need to adopt trials with recognised methods, approvals and timelines;
- there is a need to support collaboration between academic and commercial groups;

- there is a need to record any innovative experience and share it with the clinical and scientific community;
- there is a need to sustain engagement with the families who have had experience and support the new families facing the diagnosis;
- there is a need to recognise that individual families have the right to make their choice for therapies for their children;
- all practitioners must practice within the national professional regulations and international ethical guidance;
- there is a need to prioritise investment into children’s brain tumour translational research despite their commercial reputation as a “Cinderella specialty”.

What does the future hold?

These challenges offer “Moonshot

Moment(s)” to those brave enough to develop integrated, adaptable approaches to innovation, designed for their unique clinical and neuro-scientific characteristics. Other childhood cancers have been cured with total treatment programmes, using combined approaches. Real progress in this arena will permit so much more to be learnt. The personal, clinical and commercial rewards could be exceptional.

It has been my experience and privilege to witness extraordinary examples of support from the children and their families to encourage translational research in this arena. They are waiting for progress to be announced. They are willing to support innovation and collaboration. It is up to the clinician scientists to generate the opportunities the children deserve. ■

The IBTA’s 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.



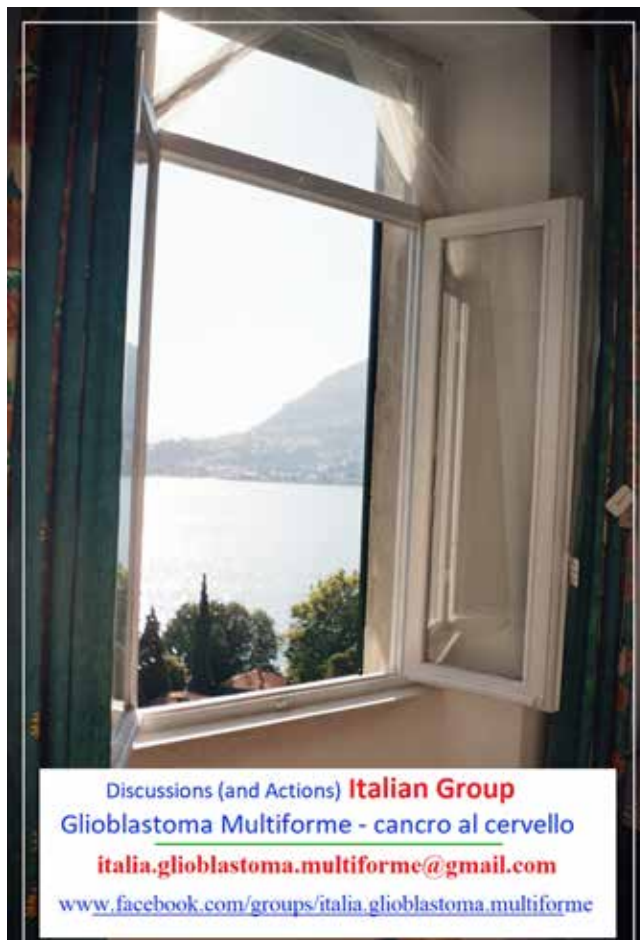
BUILDING ON SUCCESS

The Ivy Brain Tumor Center at Barrow Neurological Institute, a nonprofit clinical trials initiative for brain cancer, announced its plans to build a new 75,000-square-foot headquarters in Phoenix, Arizona. The five-story building will be the largest translational research center in the world singularly focused on accelerating brain tumor drug development.



Learn More

IvyBrainTumorCenter.org



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Ependymoma Key Issues

A collaborative exercise to raise awareness of the unique issues facing a rare brain and spinal cord tumor community



Ependymoma is a rare tumor of the brain and spinal cord that affects both children and adults. A collaborative effort between ependymoma advocacy groups across the world was organized in order to prioritize and articulate the unique key issues facing the ependymoma community. The Ependymoma Key Issues tie into the International Brain Tumour Alliance (IBTA)-initiated *Brain Tumour Patients' Charter of Rights* in order to

amplify the voice of the ependymoma community within the larger brain and spinal cord tumor community and international medical professional network in a cohesive and unified format.

Brain Tumour Patients' Charter of Rights history

On July 3, 2020, the National Brain Tumor Society (NBTS), along with more than 70 of our colleague organizations from across the international brain tumor community, welcomed the IBTA's release of an updated *Brain Tumour Patients' Charter of Rights*. The document represents the perspective of brain tumor patients and caregivers and provides a

set of standards for the healthcare experience to which all brain tumor patients and caregivers should be entitled - wherever they reside - while they navigate their treatment and live with this devastating disease.

This advocacy-based document creates a framework to help initiate positive change in the care of people diagnosed with brain and central nervous system tumors around the world. Ultimately, the goal of *The Brain Tumour Patients' Charter of Rights* is to achieve the best possible health and quality of life for adults, children, and adolescents living with brain tumors by encouraging and supporting quality standards, policies, and practices. It can be

For us, breakthroughs are personal.

Approximately one in five people will receive a diagnosis of cancer within their lifetime. But, this isn't just a number — it's us and the people we love.

That is why nothing is more personal, or more urgent, than our goal to find cures for these deadly diseases.

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EPENDYMOMA KEY ISSUES

1

EDUCATION & AWARENESS

Since there is no established standard of care for ependymoma, we call for local emergency providers and community neurosurgeons to have greater awareness of the unique medical needs of the ependymoma community, access to expert physician to physician consultation, and more educational opportunities for community providers on the latest ependymoma research and clinical practices. In addition, families should have a clear understanding of the capabilities and services offered at the facility that relate to the care they require.

Building on the IBTA Charter of Rights: Clause 2: Appropriate Investigation of Signs and Symptoms

2

CLINICAL COORDINATION

Care for patients with ependymoma requires significant coordination and collaboration. Ependymoma patients require access to multidisciplinary care throughout the trajectory of illness and survivorship. Providers should work with the family to identify who is involved in the patient's medical team, establish a point of contact for each provider, and identify who is the coordinator. The nature and rarity of the disease requires collaboration between all members of the patient's medical team on an ongoing basis with the goal of prioritizing the patient's outcome and quality of life.

Building on the IBTA Charter of Rights: Clause 3: Excellent Treatment and High-Quality Follow-Up Care

3

TRANSPARENCY

The ependymoma community has an enhanced need for evaluation or consultation by an expert neuro-oncology team at diagnosis and before any non-immediate treatment is done. This can be done in coordination with local providers or outside of that relationship. The family should receive transparent and timely communication throughout the diagnostic process and support when seeking second opinions.

Building on the IBTA Charter of Rights: Clause 2: A Clear Comprehensive, Integrated Diagnosis

4

SURVIVORSHIP & SUPPORT

It is essential that ependymoma families have a clear understanding of survivorship and known effects of treatment that can impact quality of life. Our personal goals should always be considered in each discussion about treatment and outcomes.

i.e. This might include testing like cognitive and neuropsychological evaluation done at the time of diagnosis and when possible, monitored throughout survivorship.

Building on the IBTA Charter of Rights: Clause 4: Appropriate Support

Summary Statement: People with ependymoma have an urgent need for increased funding for rare disease research that provides better targeted treatments for the different ependymoma subtypes, increases access to these treatments, and evaluates impact on quality of life. The Ependymoma Key Issues establish a framework upon which to build greater awareness and understanding of the critical issues facing patients and healthcare providers.

May 2021, Version 1

Ependymoma Key Issues graphic

continued ➤



Members of the Ependymoma Advocacy Group (EAG) during a conference call including (top row left to right) Tamiko Toland, Kim Wallgren, and (bottom row) Kim Wark

used both by professional organizations and advocacy groups as a guide for the achievement of strategic objectives to better serve the brain tumor community, and by individuals and patients to underpin particular aspects of their care.

In preparation for the 2021 Ependymoma Awareness Day virtual program, Kim Wallgren, Executive Director of the CERN Foundation (Collaborative Ependymoma Research Network), a program of the National Brain Tumor Society (NBTS), sought to further engage the ependymoma community in discussions based on the ideals set forth in the *Charter*. Following the suggestions of her colleague Danielle Leach, Chief of Community and Government Relations at NBTS, who played a role in the recent updating of the *Charter*, Kim Wallgren set out to develop key issues unique to the ependymoma community that tied into the larger international effort.

Danielle Leach said: "The opportunity to convene these groups to develop a set of issues unique to the ependymoma community sparks the advocacy efforts to create real change for this community. The robust discussion and input by these groups developed a strong statement of key needs. Basing their principles on *The Brain Tumour Patients' Charter of Rights*

illustrates how the *Charter* can be a catalyst for coalescing communities and rights-based advocacy efforts."

Creation of Ependymoma Key Issues

The initial meeting of the Ependymoma Advocacy Groups (EAG) in March 2021 included foundations that focus specifically on ependymoma, organizations that are led by an individual with a direct connection to ependymoma, and online support groups, all of which had a previous relationship with the team at the CERN Foundation and the National Brain Tumor Society. The EAG set out to identify and prioritize five key issues as a starting point with the intent to build on those initial key issues in the future.

The international group included Allyn Campbell from the **PNOC Foundation**, Liz Dawes, Kim Wark, and Cheri McCusker from the **Robert Connor Dawes Foundation**, Tamiko Toland from **Ependy Families/ Ependy Parents**, Bruce Blount from the **Adult Ependymoma Online Support Group**, Linda Rickford from the **Astro Brain Tumour Fund**, Christine and Andrew FitzPatrick from the **Tommy Strong Foundation**, and Danielle Leach, Rachael Kittleson, and Kim Wallgren from the **National Brain Tumor**

Society. In addition, Chas Haynes from the **Society for Neuro-Oncology (SNO)** and Kathy Oliver from the **IBTA** joined the discussion and provided feedback.

Through online discussions, surveys, and multiple rounds of editing, the group was able to distill the initial ideas into four ependymoma key issues along with a summary statement. Each participant contributed important experience and feedback that helped to shape each issue. The final Ependymoma Key Issues were released at the 2021 Ependymoma Awareness Day virtual program through the voices of the contributors themselves. Ependymoma Advocacy Group members submitted videos of themselves or a stakeholder reading one Ependymoma Key Issue. In addition, a creative graphic was designed in order to share and distribute the Key Issues document through professional and patient channels as a means to raise awareness about the effort.

Different Approach Needed for Rare Disease Advocacy

Relationships are key to any collaboration. In addition, when focusing on rare disease advocacy, it is imperative to think outside the box of traditional nonprofits

and organizations. For example, CERN has been collaborating with Tamiko Toland and Bruce Blount for years. Both of these individuals lead online support groups that aren't traditional 501c3 organizations or formal groups with a budget and staff. However, they make a tremendous impact in the ependymoma space and have unparalleled experience with ependymoma as a rare disease. Input from Tamiko Toland and Bruce Blount is vital to any activity designed to raise awareness and impact change and illustrates the need to include non-traditional efforts if we are going to capture the true nature of this community.

Though differences exist between the diagnosis and treatment of adult and pediatric ependymomas, when representatives from these respective populations work together the collective advocacy voice for the ependymoma community benefits. Together, we are able to make a larger impact while also beginning to bridge the gap and represent the young adult population into which many ependymoma survivors fall.

This Ependymoma Key Issues effort serves as a critical example for other groups that are looking for a launching point to address how their unique challenges and opportunities fit within the larger narrative needs of the global brain tumor community. It shows how even disparate groups with limited resources can band together, leverage existing infrastructure and create a meaningful advocacy and awareness effort.

"With some frequency, we talk with advocates and community members and they ask, 'Why hasn't this been done before?'," said Kim Wallgren. "Chances are it has or has at least been considered. We need to take the time to evaluate and understand what tools, programs, and knowledge already exist and work with groups to customize initiatives to meet the unique needs of their group or organization, without duplicating efforts. When you focus on a rare disease, you are forced to look for opportunities to join larger efforts, while keeping the important independent focus at the forefront of decisions and strategy. By the nature of rare disease work, we have to collaborate and rely on each other and that is best done within a community built on trust and mutual respect."



Ependymoma Key Issue shared by Christine and Andrew Fitzpatrick from the Tommy Strong Foundation in the 2021 Ependymoma Awareness Day virtual event



Ependymoma Key Issue shared by Allyn Campbell from the PNOC Foundation in the 2021 Ependymoma Awareness Day virtual event

It is intended that *The Brain Tumour Patients' Charter of Rights* will be reviewed and updated periodically. NBTS will continue to sit on the *Charter* drafting committee to contribute to this update and review process. Other organizations can still sign on as supporters of the *Charter* and will be added on a rolling basis. Likewise, a date and version number were included on the first iteration of the Ependymoma Key Issues because like the *Charter*, the content was developed through a multi-stakeholder and iterative process and is a "living document", subject to annual review. We hope to build out these key issues and possibly add further criteria to support the unique challenges experienced by those affected by ependymoma. ■

If your group or organization has a specific interest in the ependymoma discussion, please contact kwallgren@braintumor.org

To read *The Brain Tumour Patients' Charter of Rights* (available in multiple languages), please see magazine pages 115-127 and visit <https://theibta.org/charter/>. If your organization is interested in becoming a supporter of *The Brain Tumour Patients' Charter of Rights*, please contact kathy@theibta.org

Welcome to the ISPNO 2022 Hybrid Meeting

Dear Friends, Colleagues and Supporters of the Pediatric Neuro-Oncology Community,

It is our great pleasure to invite you to join the 20th International Symposium on Pediatric Neuro-Oncology - ISPNO 2022 (June 13-15) - and the Annual Meeting of the Brain Tumor Group of SIOP-Europe (June 11-12) in Hamburg, Germany.

ISPNO 2022 will be the first ISPNO meeting to be held in Germany, and we are expecting approximately 1,000 in-person delegates for this hybrid meeting. The meeting will be co-hosted by the University Medical Center Hamburg-Eppendorf and the German Cancer Research Center (DKFZ) Heidelberg, the largest biomedical research institute in Germany which, together with Heidelberg University Hospital, serves as a mother institution for the Hopp Children's Cancer Center (KITZ) Heidelberg.

The program for this hybrid meeting will include the most recent cutting-edge preclinical and clinical research from the fields of neurosurgery, neuroradiology, neuropathology, neurobiology, radiotherapy, pediatric neuro-oncology, immunotherapy, late effects, rehabilitation, and nursing.

We look forward to seeing you all in June 2022 in Hamburg, Germany!



Left: Prof. Dr. med. Stefan Rutkowski, Chair of ISPNO 2022; Speaker of the Pediatric Brain Tumor Study Group of GPOH (HIT-Network); Department for Pediatric Hematology and Oncology and Centrum for Obstetrics and Pediatrics, University of Hamburg, Germany
Right: Prof. Dr. med. Stefan M. Pfister, Chair of ISPNO 2022; Director Preclinical Program, Hopp Children's Cancer Center (KITZ), Heidelberg, Germany; Deputy Head, KITZ Clinical Trial Unit (ZIPO) and Pediatric Brain Tumors, Heidelberg University Hospital, Germany.
Photo of Dr. Pfister: ©Philip Benjamin 2016 · pbenj@me.com

ISPNO
Hamburg 2022

The 20th International Symposium on Pediatric Neuro-Oncology
13 – 15 June 2022
SIOPE Brain Tumor Group Meeting
11 – 12 June 2022
www.ispno2022.de

Chairs:
Stefan Rutkowski (Hamburg)
Stefan Pfister (Heidelberg)

Venue:
Congress Center Hamburg

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Time To Act: European Cancer Organisation calls for urgent action as one million cancer cases could be undiagnosed in Europe due to COVID-19

European Cancer Organisation (E.C.O.)



Stella Kyriakides, European Commissioner for Health and Food Safety, speaking at the Time To Act campaign virtual launch in May 2021

Nearly one million cancer cases in Europe are being missed due to Covid-19, according to new data published by the European Cancer Organisation (E.C.O.). The findings, a stark reminder of the challenges facing cancer care services in Europe during the pandemic, coincide with the launch of 'Time To Act', E.C.O.'s campaign to urge the public, cancer patients, policymakers and healthcare professionals to ensure Covid-19 does not continue to undermine the fight against cancer. The campaign also calls for every country in Europe to achieve the promptest restoration of cancer

services to avoid the Covid-19 pandemic from creating a new cancer epidemic in its wake.

The new data intelligence places the scale of the crisis in startling relief:

- An estimated **1 million cancer cases could be undiagnosed** in Europe due to the backlog of screening tests, reduction and delays in referrals as well as restricted healthcare resources.

- An estimated **100 million cancer screening tests were not performed** in Europe, leading to later stage diagnoses and decreased overall survival.

- **Up to 1 in 2 people with potential cancer symptoms** were not urgently referred for diagnosis.

- **Clinicians across Europe saw 1.5 million fewer cancer patients** in the first year of the pandemic.

- **1 in every 5 cancer patients** in Europe is currently still not receiving the surgical or chemotherapy treatment they need.

Action is needed

Such data demonstrates the urgent demand for action, and action is indeed what punctuates [continues on page 38](#) ➤

Nu lăsați COVID-19 să vă împiedice în combaterea cancerului

Μην αφήσεις την COVID-19 να σε εμποδίσει να αντιμετωπίσεις τον καρκίνο

Låt inte Covid-19 stå i vägen för
din cancervård och behandling

Nie pozwólmy, by Covid-19 zatrzymał walkę z rakiem

Nenech COVID-19, aby stál v cestě tvému boji s rakovinou

Ne engedje, hogy a COVID-19 megakadályozza a rák elleni küzdelemben

Covid-19 darf der Behandlung von Krebs nicht im Wege stehen

Mos lejo që Covid-19 të
ndërpresë trajtimin e Kancerit

La Covid-19 ne doit pas être un frein
aux soins contre le cancer

Ne dopustite da vas Covid-19 spriječi u borbi protiv raka

Laat Covid-19 u er niet van weerhouden kanker aan te pakken

Ne dovolite covidu, da vas
ustavi pri obvladovanju raka

Amser i Weithredu. Peidiwch â gadael i
Covid-19 eich atal rhag taclo Cancr

Wherever
you are...

Ärge laske Covid-19-l end
takistada vähiga võitlemisel

Älä anna Koronan estää
syöpäseulontaa

Don't let COVID-19 stop you from tackling cancer

Ez utzi COVID-19 Minbiziari aurre
egiten eragozten

Nedovol'te, aby Vám Covid-19 zabránil v boji proti rakovine

Lad ikke Covid-19 stoppe kampen mod kræften

Il Covid non deve
fermare la lotta
contro il Cancro

Ne dovolite da vas COVID-19 zaustavi u borbi protiv raka

Ikke la Covid – 19 hindre
deg i å takle kreft

Älä anna Koronan estää syöpäseulontaa

Не позволявайте на Covid-19 да възпрепятства борбата с рака

Tá sé rithábachtach nach gá do Covid imscrúdú a dhéanamh ar Ailse

Не дайте Covid-19 помешать
Вам бороться с раком

No dejes que el COVID te
impida hacer frente al Cáncer

Neleiskime Covid-19
stabdyti mūsų kovos
su vėžiu

Neļauj Covid-19 apturēt Tavu cīņu pret vēzi

'Covid-19'un Kanser Kontrol ve Tedavinizi Engellemesine İzin Vermeyin

Não deixe que a COVID-19 o impeça de enfrentar o cancro

the very name and essence of this campaign. Its strapline, “Don’t let Covid-19 stop you from tackling cancer”, is a clear statement of what is set to be achieved.

The all-encompassing ambition of the Time To Act campaign is to address the huge cancer backlog and encourage the reimagining of cancer services in order to build back better, smarter and ultimately more resilient. Through making this a reality, E.C.O., with the support of the Time To Act campaign supporters and other stakeholders, hopes to assist cancer patients in going to their appointments, planning new ones and safely receiving the care they deserve.

Insisting that citizens watch out for early warning signs of cancer, and consult their doctor to get checked, is an additional step the campaign is taking to ensure that individual health doesn’t get neglected amidst the pandemic. As for healthcare professionals, providing them with reassurance and most importantly with a well-equipped workforce that they can rely

on, is fundamental if we are to combat not only cancer, but other potentially fatal diseases too that have further dropped in the list of urgencies since the start of Covid-19.

The Time to Act Campaign

With the aim of reaching a pan-European audience, E.C.O. has created an inclusive array of campaign materials in over 30 languages, which can be found on the Time To Act website: www.TimeToActCancer.com. Accompanying this, is the stat-driven data intelligence hub, a rich library of resources on cancer and Covid-19, a 7-point plan strategising the build back better movement, an illustrative inventory of cancer warning signs and a united section of dedicated elected officials from varying parties at European level having added their voice to the campaign.

The official launch of the Time To Act campaign took place on 11 May 2021 in the form of a virtual live event complete with over 20 high-level

speakers considered as authorities on the topic, including EU Health Commissioner Stella Kyriakides, European political leaders in cancer, the Chair and MEPs from the European Parliament’s Special Committee on Beating Cancer (BECA), policy-makers, healthcare professionals and patient advocates.

To add to the momentum, we are encouraging the whole of Europe to act now by launching a variety of national campaigns, with Poland, Italy and Spain having already paved the way for Romania and others later this year.

While serious attention given to the pandemic is entirely justified, it must be said that cancer won’t wait. We urge national governments to not risk cancer becoming the forgotten ‘C’ in the chaos caused by Covid-19. If society fails to act on the facts, we could soon be faced with an even sharper rise of cancer cases. With this in mind, there are no better words to emphasise that it truly is **Time To Act**. ■



Over 1 million cancer cases could be undiagnosed in Europe because of Covid-19.


IT'S TIME TO ACT.

Don't let Covid-19 stop you from tackling Cancer.

TimeToActCancer.com
#TimeToActCancer

TIME TO ACT.

europa
cancer



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

Association pour la Recherche sur les Tumeurs Cérébrales
Groupe Hospitalier Pitié Salpêtrière
Fédération de Neurologie – Mazarin
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IL FONDO DI GIO

Gio's Fund for research on brain tumors
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Among projects supported: clinical studies for the treatment of diffuse intrinsic pontine glioma (DIPG); engineered T cells for the treatment of glioblastoma; molecular stratification of high grade glioma in children; dendritic cell immunotherapy of glioblastoma.

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per la ricerca sui tumori cerebrali
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Selected rare adult brain and spine tumor types:

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- Choroid Plexus Tumors
- Diffuse Midline Gliomas
- Ependymoma
- Gliomatosis Cerebri
- Gliosarcoma
- Medulloblastoma
- Meningioma (High Grade)
- Oligodendroglioma
- Pineal Region Tumors
- Pleomorphic Xanthoastrocytoma (PXA) and Anaplastic Pleomorphic Xanthoastrocytoma (APXA)
- Primitive Neuro-Ectodermal Tumors (PNET)

Contact us at **NCICONNECT@mail.nih.gov** or **(240) 760-6530**.

NCI-CONNECT is managed at the National Institutes of Health, National Cancer Institute Center for Cancer Research Neuro-Oncology Branch.

SwissNOS – a vibrant neuro-oncology community

Prof Dr med Michael Weller, Chairman

Department of Neurology, University Hospital, Zurich, Switzerland



The Swiss Neuro-Oncology Society (SwissNOS) was founded in December 2019 in Zurich, Switzerland. The first officers of the Society are Michael Weller (President), Silvia Hofer (Secretary) and Andreas Hottinger (Treasurer).

SwissNOS now comprises 40 active members from all disciplines involved in neuro-oncology and from all parts of Switzerland. Fourteen members are neurologists, eight neurosurgeons, five radiation oncologists and eight medical oncologists, two neuropathologists, one pediatrician and two basic neuro-oncology researchers. The age distribution of the SwissNOS members ranges from 28 to 65 years. SwissNOS is open to all professionals who are actively involved in the diagnosis, oncological treatment, general care, and follow-up of patients with tumors of the nervous system, as well as researchers active in the field of neuro-oncology.

In 2020, SwissNOS held two multidisciplinary virtual meetings, on April 7 and on October 22. In 2021, two further meetings took place on March 3 and on June 22. The main topics discussed at these meetings were coordinating research in Switzerland, developing Swiss-specific algorithms for diagnosis and treatment, maintaining our network through the pandemic, and exchanging information on ongoing projects, notably clinical trials. The first official public annual conference of SwissNOS is planned for September 17-18, 2021, in Lausanne, Switzerland.

SwissNOS has published two position papers so far, one on *A Contemporary*



Founding of SwissNOS in 2019 (from left: Monika Hegi, Michael Weller, Silvia Hofer, Thomas Hundsberger, Philippe Schucht, Patrick Roth, Andreas Hottinger, Ulrich Roelcke)

perspective on the diagnosis and treatment of diffuse gliomas in adults (2020) and another on Fitness-to-drive for glioblastoma patients, A Guidance from the Swiss Neuro-Oncology Society (SwissNOS) and the Swiss Society for Legal Medicine (SGRM) (2021), in the journal Swiss Medical Weekly.

The SwissNOS website is open to the public (<https://www.swissnos.com>). There, under the different headings, currently recruiting studies in Switzerland are visible for our members, links to the EANO (European Association of Neuro-Oncology) guidelines can be activated, future events are announced and SwissNOS projects are described. Current projects in progress are to develop a teaching program for young colleagues, to promote international

exchange, notably with neuro-oncology societies of the neighboring countries, and to organize an annual patient day.

The Swiss Neuro-Oncology Society works in close cooperation with the Swiss Brain Tumor Foundation that seeks to establish a first forum for patients with brain tumors and their caregivers across Switzerland. The development of this forum has remained challenging, because of the multiple languages in our country, and notably because of the Covid 19 pandemic. ■

For further information on
SwissNOS, email:
contact@swissnos.com

Improving patient-reported outcome assessment in clinical care and clinical studies for brain tumour patients

On behalf to the RANO-PRO Working Group and Fast Track COA Group:

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Dr Linda Dirven

For patients with a brain tumour, it is important to evaluate the impact of the disease and its treatment on how they feel and function.

Outcomes on symptoms and functions are typically measured with questionnaires, which are considered patient-reported outcome (PRO) measures. PRO measures might focus on an individual or multiple symptoms (e.g. pain or seizures), activities in daily life (e.g. doing household chores or working), mood and emotional states (e.g. anxiety



Professor Martin Taphoorn

or depression) and overall level of health-related quality of life.

In clinical care and clinical studies, the results of PROs can provide additional information about the beneficial and adverse effects of (new) treatments, adding context to information obtained with imaging or a physical examination. Patients, their relatives, and physicians can use the information obtained with PRO measures in daily clinical practice to make well-informed treatment decisions. Also, PRO results can be used to monitor symptoms and functions of patients



Dr Terri Armstrong

during the disease trajectory. In this way, opportunities for symptom management could be identified throughout the disease trajectory.

In clinical studies, patient-reported outcomes are used to weigh the benefits and adverse effects of new treatment strategies. That means that the possible benefits of prolonged survival are weighed against the negative side-effects of the treatment on how the patient feels and functions. Regulatory agencies (e.g. the US Food and Drug Administration, FDA, and the European Medicines Agency, EMA) use this information

continued ►

in their decisions to approve a new treatment for use in daily clinical practice.

Results of PROs, together with information from imaging and physical examinations, are crucial to inform patients, their relatives, physicians, and regulatory agencies on the impact of treatment. It is therefore important that the PRO measures that are used to measure outcomes are not only relevant for brain tumour patients, but also of high quality.

Providing guidance on the use of PRO measures for brain tumour patients

In 2017, the Response Assessment in Neuro-Oncology – Patient-Reported Outcome (RANO-PRO) working group was established. This international collaboration aims to provide guidance on the use of PRO measures in clinical care and clinical studies for adult patients with brain tumours.

As a first step, the literature was searched to identify PRO measures that are currently used in brain tumour studies. This literature review showed that 215 different questionnaires were used to measure symptoms, activities of daily life and/or overall health-related quality of life in patients with brain tumours. An important finding was that the majority of these questionnaires were only used once or twice. As a second step, we aim to determine whether the items in these identified questionnaires are relevant for brain tumour patients. This is necessary because not all questionnaires that were identified in the literature review were developed for brain tumour patients specifically. Instead, some are developed for the general population or patients with another disease, such as dementia or traumatic brain injury. This means that the items included in these questionnaires may reflect issues that are important to other patient groups, but not to brain tumour patients. It may also be that relevant issues specifically for brain tumour patients are not covered by these questionnaires, such as seizures, problems with concentration or weakness of legs.

To determine which aspects of functioning are relevant to adult brain tumour patients, we set up an international survey. This survey comprises 148 questions reflecting symptoms and impairments, and functioning in daily life, as specified by the World Health Organization in their International

Classification of Functioning, Disability and Health (WHO-ICF) framework. Currently, the survey is administered to adult brain tumour patients and their relatives, as well as health care professionals worldwide. Participants are requested to indicate the relevance of each item (e.g. 'Lack of energy?') on a scale ranging from 'not at all relevant' to 'very relevant'. The results of this survey will help us to establish which aspects of functioning are most important to brain tumour patients. Subsequently, we will evaluate to what extent the 215 identified questionnaires reflect these relevant items, and which aspects are currently not covered by the available questionnaires. This will help the research community to select those questionnaires for use in clinical practice and studies that best reflect the issues of brain tumour patients.

Although the work done by the RANO-PRO working group is important, this is a time-consuming process. In the meantime, there was an urgent need from the neuro-oncological community and the regulatory agencies to establish a core set of symptoms and functions for use in clinical practice and studies for patients with high-grade gliomas. This core set of symptoms and functions refers to those aspects that should always be assessed as the minimum in both clinical care and research; the addition of other relevant aspects depends on the individual patient or clinical study.

The Fast Track Clinical Outcome Assessment Group

To develop such a core set of symptoms and functions, the Fast Track Clinical Outcome Assessment (COA) Group was established, including members of the RANO-PRO working group, regulatory agencies and patient organizations. This Fast Track COA Group built on previous work done by the Jumpstarting Brain Tumor Drug Development (JSBTDD) Clinical Outcomes Workshop in 2014, in which key areas for outcome assessment in clinical studies for glioma patients were identified.

One of the aspects of the JSBTDD initiative was a review of the literature to identify symptoms and functions in patients with high-grade glioma, as well as an online survey among patients and relatives on the importance of presented symptoms. These

results guided the discussion among the Fast Track COA Group members in prioritizing the symptoms and functions that should at least be assessed in clinical care and research. If all clinical studies will measure this core set of symptoms and functions, the results of these studies can be better compared.

The work resulted in the identification of four core symptoms, i.e. pain, difficulty communicating, perceived cognition (e.g. attention and concentration) and seizures. In addition, it was deemed important that symptomatic side-effects of treatment should be assessed (e.g. fatigue, or nausea and vomiting), but this choice should be based on the available knowledge on side-effects of the treatment under investigation.

Besides these core symptoms, two core functional constructs were deemed important: physical functioning to include walking, and role and social functioning (i.e. related to taking care of family members, working and engaging in social activities). As mentioned, these core symptoms and functions are the minimum patient-reported outcomes that should be assessed in patients with high-grade glioma. If considered relevant, other aspects (e.g. symptoms of anxiety and depression) can of course be added to these core constructs, although this may result in an additional burden for the patient. The next step is to evaluate the sensitivity of these core constructs in existing observational and finished clinical studies. In the interim, clinicians and researchers are encouraged to use existing well-validated scales to measure these constructs in clinical care and clinical studies.

In conclusion, the RANO-PRO working group and Fast Track COA group aim to provide guidance on the use of PRO measures in clinical care and studies for patients with brain tumours. Currently, consensus among members of the neuro-oncological community with respect to the instruments to measure core symptoms and functions, the timing of the assessments during the disease course, and analytical methods needs to be established, and can build upon existing guidance in the oncology community. By establishing a core set of symptoms and constructs, identification of appropriate instruments to measure outcomes, and standardisation of analytical methods, our understanding of the impact of the treatment on how brain tumour patients' feel and function will be improved. ■

The Arcagen project and central nervous system tumours

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EORTC HQ, Brussels, Belgium



An introduction to rare cancers

Rare cancers, of which brain tumours are an example, represent about 20% of all adult cancers, but 30% of cancer mortality. The over mortality of rare cancers compared to other cancers can be explained by misdiagnosis, delays in diagnosis, limited research efforts in the past, lack of optimal guidelines, and insufficient research today.

In the European Union, a cancer is considered rare when its incidence is lower than 6 per year out of 100,000 people. Rare cancers are clearly under-represented in the research programs exploring genomic alterations of cancer. Therefore, little is known regarding prevalence of clinically actionable genomic alterations in rare cancers in general. Translational and clinical research on

rare tumours has long been hindered by organizational difficulties linked to dispersed populations of patients, limited efforts for tumour collection, and inaccurate diagnosis.

Overall, in Europe about 28,000 new rare central nervous system (CNS) cancer cases are diagnosed each year and more than 150,000 people are living with the disease (Crocetti et al., 2012). In the United States, the overall incidence for all 12 rare CNS sub-types combined is about 1.5 per 100,000 people, and relative survival varies significantly, depending on the sub-type (Tritt et al., 2019).

What is Arcagen?

The Arcagen project, set up in 2018, will allow researchers and clinicians to gain a strong understanding of the molecular landscape of rare cancers in Europe and

provide a rationale and hypothesis for future clinical research on rare cancers in order to hopefully achieve a strong benefit for patient care.

The project will analyse 1,000 patients diagnosed with a rare cancer as defined by the European Reference Network (ERN) for rare adult solid cancers (EURACAN), including rare tumours of the central nervous system. The project is a collaboration between the European Organization for Research and Treatment of Cancer (EORTC, Brussels, Belgium), the European Reference Network (ERN) for rare adult solid cancers (EURACAN) headed by Professor Jean-Yves Blay (Centre Léon Bérard, Lyon, France) and the pharmaceutical company F. Hoffmann-La Roche (Basel, Switzerland) which is providing the molecular testing for

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all patients. The CNS cohort is led by Professor Ahmed Idbaih and Professor Enrico Franceschi, the EURACAN “domain” (or “subgroup”) lead and co-lead for rare CNS tumours.

Who can participate in the Arcagen project?

The Arcagen project is recruiting patients via the EORTC SPECTA platform.

SPECTA is a collaborative European platform that facilitates the recruitment of cancer patients for clinical trials and further translational research on cancer. The platform is currently open in more than 100 centres across 17 European countries. The CNS domain of EURACAN is currently recruiting patients with rare CNS tumors, with specific focus on spinal cord tumors and ependymomas. Clinicians only need to be authorized to recruit patients in the SPECTA platform before registering patients for molecular profiling in Arcagen.

After a medical review to confirm a patient’s eligibility and quality checks performed on the patient’s collected tissue sample at the central biobank, samples are sent to the central laboratory of the company Foundation Medicine for molecular analysis. Within four weeks of patient enrolment in Arcagen, the clinician is provided with a molecular report, describing the patient’s molecular profile and potential therapies associated with that profile. If needed, molecular tumor boards with clinicians, pathologists and molecular biologists could be organised to discuss different cases and patient care.

Recruitment to Arcagen started in June 2019 and should continue until the end of 2022 by which time it is hoped that 1,000 cancer patients will be enrolled in the project, including those with central nervous system tumours.

The Arcagen global project recruitment is extremely positive with 746 patients already recruited. Molecular reports have been generated for 530 patients and shared with clinicians. Due to the low incidence of CNS tumours, only 16 patients have been enrolled in the Arcagen project so far, leaving several slots still open for additional recruitment.

The Arcagen study is funded by F. Hoffman-La Roche. The SPECTA platform is supported by the Walgreen Boots Alliance. ■

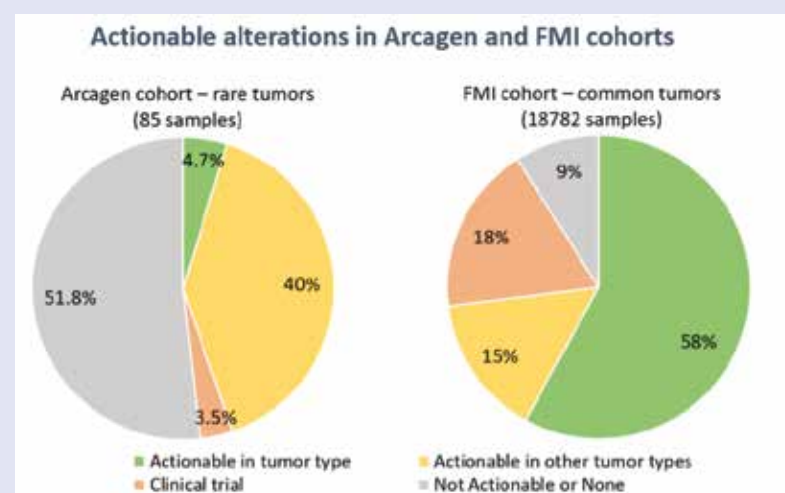
First results from the Arcagen project pilot

The first results for the Arcagen projects were published in the journal *ESMO Open* in 2020 (Morfouace et al., 2020). This publication focused on the first 77 patients recruited during the pilot phase of the project, with a diagnosis of sarcoma, rare head and neck cancers, yolk sac tumours or thymic malignancies.

This pilot study highlighted the fact that research on rare cancers is crucially needed. As illustrated below, researchers were unable to find actionable mutations in more than half of the patients with a rare cancer (left graph), compared to only 9% of patients with more common tumours (right graph).

This highlights the fact that the mutational landscape of rare cancers is not well known and is less frequently covered by current commercial sequencing panels (sequencing panels focus on analysing a defined set of genes, important for tumor development and progression). Moreover, for 58% of common cancers, the identified molecular alterations were actionable within the same tumour type (approved by the European Medicines Agency - EMA), whereas only 4.7% of alterations in rare cancers were in this situation, but 40% of rare cancer alterations were actionable in other, more common tumour types.

This led to the fact that clinical research on rare cancers and inclusion of rare cancers in clinical trials are also needed (and not just focussing on the assessment of common cancers) to assess if specific targeted therapies can have an effect, independent of tumour type. ■



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

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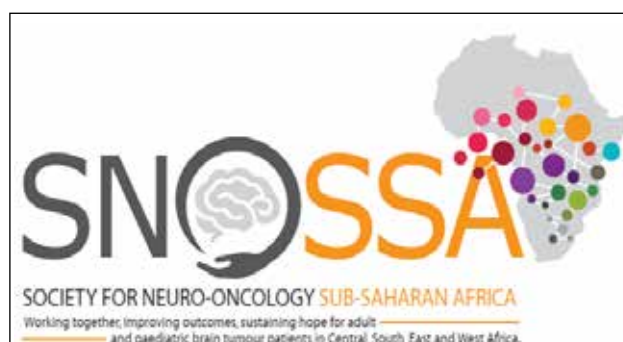
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Why Brainy?

Dr Gaetano Finocchiaro
 Department of Neurology, IRCCS Ospedale San Raffaele, Milan, Italy



In November 2020, in the middle of the COVID-19 pandemic in Italy, seven people - the members of two families badly hit by glioblastoma in Bergamo and Milan, along with two neurologists from Padua and Milan and a new doctor from Genoa - went to a notary in Milan, to officially register Brainy, a new organisation addressing the challenges of brain tumors in our country.

We thought of the name Brainy for our organisation for a while. The name had been proposed some time ago by a close friend of one of the founders. Quite likely, she wanted to provide some lightness and a pinch of irony to a deeply-felt concept we all shared, starting from very different points of view: that it is time to offer much more to patients affected by brain tumors and particularly by malignant gliomas.

As an example, one of the founders could clearly (and sadly) remember that her husband was offered the same treatment his own father was offered to treat the father's glioblastoma some twenty years earlier with, unfortunately, a similar perspective in terms of time left

from diagnosis, and quality of life during that same time.

We, at Brainy (families, caregivers, students, physicians and scientists) all share the same basic concept: only scientific research will change the scenario that we have all witnessed, even if we have looked at it from different perspectives; that grim sense of inevitability which you have when you are left with the only possibility - to stretch the time available to the patient as much as possible.

We want to change this, starting from little steps and trying progressively to expand our ambitions. For this it would be important to check all the existing charities devoted to brain tumor patients in Italy and see whether we may come together in some form of collaboration - but still leaving to each group its autonomy - and

try to focus on one (or more, in the future) common objectives as part of each effort and funding. IBTA could probably be of great support in this endeavor. Ideally, such an approach could also be extended to different European countries.

One distinct point at Brainy is the appreciation for high-quality science, as great science is crucial to yielding tangible results that are meaningful to the patient community. For this, we have asked four outstanding scientists to collaborate with Brainy regarding the definition of scientific objectives and the evaluation of the proposals that we will receive after a research call. To start with, we should be able to finance, by the end of this year, a one-year fellowship for research in neuro-oncology. Our Brainy Scientific Committee will guarantee the transparency and quality of all procedures. ■

At present, our website (www.associazionebrainy.com) is only in Italian. But an English version will be ready in the near future. Right now we can provide readers with the English version of the nine points summarizing the ideas behind the creation of Brainy:

1. Brainy stands for clever.
2. Brainy refers to the brain.
3. You need to be brainy to fight brainy enemies such as brain tumours, selected to survive heavy challenges.
4. To study the brain, an extraordinary organ, is critical: the more we understand how it works, the more we can realize how it gets sick.
5. To this end, we need knowledge, creativity, culture, and a quest for quality.
6. We need intellectual probity and integrity to challenge false science.
7. We must put energies, resources, and organization into a common objective: to know better and thus fight brain tumours more effectively.
8. We have joined together physicians, patients, and scientists to play their part in the long chess game against brain tumours which are these ingenious and malignant foes.
9. This is why Brainy was created.

Left: Brainy's founders: (left to right) Laura Muccini, Eva Cividini, Gaetano Finocchiaro, Gianluca Cividini, Viola Finocchiaro and Annamaria Bruno; not pictured: Chiara Briani. Photo by greenmarketing.it

He waka eke noa!

Brain Tumour Support NZ's call to the nation

Mandy Bathan

Chairperson, Brain Tumour Support NZ

In September 2017 I was 53 and living a busy life as a primary school teacher, helping five-year-old children to learn maths and to read and write.

As a mother of three children who were sort of grown up - one married, one working and one at university - I had a regular life most of us would recognise involving paying bills, juggling schedules and being with my grandson. The only contact I'd ever had with brain tumours were the sort of thing portrayed on slick American hospital TV shows where impossibly good-looking surgeons and an assemblage of equally beautiful staff would perform last minute lifesaving miracles to the satisfaction of themselves and of course me the viewer. The end credits would roll by and for me, give or take a few road bumps, life was a place of children's laughter as well as dealing with the usual minutiae of life.

Then abruptly and without warning things changed. I was diagnosed with an oligodendroglioma.

A new journey starts

My new chapter began with only the vaguest of symptoms. There were no blinding headaches or seizures (or so I thought). Only difficult-to-explain 'weird sensations.' On the gut feeling of my local GP, I was referred for an EEG and then subsequently for a 'routine' MRI which everybody agreed was a good option 'to discount anything sinister'. However, the results rapidly changed my life, and I was swept into a sequence of hospital gowns, blood draws and technicians working to the cacophony of shrieks and rowdy bangs of MRI machines.

Life became a cycle of earplugs in, claustrophobic masks on, breathe in, breathe out, medication taken, dye

injected, moving, or being moved. I had morphed from a woman made of feelings and flesh into a patient of light and shadows. I was now forever to be attended to by quietly spoken nurses as well as a range of specialist surgeons, whose roles had previously only been familiar to me from TV hospital dramas. My new life also included the sounds of various monitors and devices whose beeping, squawking, and buzzing would orchestrate themselves with the harsh flat light of hospital wards.

In my previous life, the word 'oligodendroglioma' would have earned a twenty-two-point Scrabble score, now it earned a fearsome reputation as a term to be both feared and studied. An operation was scheduled and after several false starts caused by a pesky overactive thyroid, I had the six-hour resection of my tumour. At least, the surgeon called it a resection but stressed



Mandy and her husband, Stuart, with baby grandson Rufus

that there was still 'some' there; I struggled to make sense of what this all meant.

After my surgery came a petrifying carousel of follow-up appointments to discuss various chemotherapy and radiotherapy options. I used my nursing knowledge to research statistical outcomes, risks and benefits, trade-offs and best practice concerning my new life. Although websites carried lots of information it seemed dazzlingly contradictory and overwhelmingly complicated (especially post brain surgery). I realised that there had to be a better way to help brain tumour patients and their families here in New Zealand.

And just like that I decided to set up a charity to help others navigate the warren of obfuscated information and blind alleys of brain tumour information on the web.

Brain Tumour Support NZ is born

From my home in Nelson, South Island, New Zealand, I realised there was no single source of information on brain tumours for New Zealanders to access. Like me, others diagnosed with a brain tumour here had spent too much unproductive time trying to figure out tangled threads of data and information from websites across Canada, UK, USA, and Australia. This often held little

relevance for people living on the remote West Coast of New Zealand nor indeed in the sprawl of Auckland, where people would find themselves alone, working through a geographically distanced opaque health system. There had to be a way to help vulnerable patients and families, especially here in New Zealand.

I decided to use a Māori proverb or whakatauki to proclaim a call to the nation: He waka eke noa - we are all in this together. (Māori are the indigenous people of New Zealand and these proverbs are

He waka eke noa!

(We are all in this together)

often used by New Zealanders to help make sense of the world.) Fortified with nothing more than my phone and my laptop I decided to start the Brain Tumour Support NZ charity with its aim to provide information, support and guidance to patients, their families, and friends across all of Aotearoa, the Māori name for New Zealand.

At this point I had never set up a charity before and had to muster all my strength and tenacity to overcome my own nagging inner voices of self-doubt which had increased significantly following diagnosis, as well as trying to recover from my treatment.

How do I exactly start a charity? How do finances work? Am I good enough? I spent hours making connections with specialists across New Zealand and after explaining my mission, managed to garner other people's time and energy, either in an advisory role or as formal board members.

My close friend Marie Waterhouse volunteered her website and design business HotHouse Creative to craft a smart brand and website to fully support the vision. I also formed a close bond with Chris Tse, New Zealand's Senior Advisor to the International Brain Tumour Alliance (IBTA) and Gavin Starling whose life partner Natalie had recently died of a glioblastoma. All three gave their time, knowledge and resources and joined the board. This critical mass of Marie, Chris, Gavin, and myself gave birth to Brain Tumour Support New Zealand (BTSNZ).

Providing support and information to brain tumour patients in New Zealand

Suddenly we were immersed in long meetings discussing and fine-tuning governance policies to support the vision of the charity. Legal deeds and tax forms were completed and accountant, John Brydon, was brought onto the board. All board members freely gave their precious time, showing depth of character and strength of service to fulfil the challenge: if you hear the words 'you have a brain tumour' BTSNZ will be there to provide the support you need.

I am proud to say that in 2021, these lovely people are still committed to improving the life of everyone affected by a brain tumour in our country and to

continued ►

Mandy and her dog, Frankie, walking on Ngarunui Beach, Raglan, New Zealand



Mandy and her family on a day out at Bridal Veil Falls, Raglan, New Zealand. Baby Rufus, Mandy's grandson, is in the baby pouch.

defend the most incredible part of the human body.

COVID-19 takes its toll

2020 was a difficult year for us all – perhaps the most difficult that many of us have experienced. On 28 February 2020 the first COVID-19 case was reported in New Zealand and the government reacted quickly by announcing on the 19th March that the borders were closed to all but New Zealand citizens and permanent residents, with full lockdown beginning just days after. The country was in shock.

Since the COVID-19 pandemic began, thousands of medical procedures and appointments here in New Zealand have been cancelled or delayed. The long-term effects of these drastic measures on brain tumour patients and caregivers are, at present, hard to quantify. We have many anecdotal reports about the increased fear, late referrals, delayed treatments and follow

up appointments, as well as people with brain tumour symptoms delaying referring themselves to their doctor. Early in 2020 my own MRI was delayed by three months and even now, when I should be having yearly MRIs, I find I'm still waiting, 18 months later. I can only imagine how awful it was, and still is, for those going through diagnosis and treatment during this time. Evidence suggests that our health service here is still struggling to catch up.

We know that the severity of COVID-19 can vary from person to person, and that those who are immunosuppressed are at the highest risk. Our brain tumour community is vulnerable to high levels of stress. Going through a major life event, as is the case when you discover that you have a brain tumour, brings a series of emotional reactions which creates significant psychological strain. This increased burden often causes patients to experience difficulties in returning to their



Mandy with newborn grandson Rufus

pre-diagnosis state and severely impacts their quality of life and the people who surround them.

Onwards and upwards!

We have worked hard to support our New Zealand brain tumour community through this time, with our number one priority being to ensure that members of our community are safe and well.

Like all non-profits, BTSNZ is powered by the passion and dedication of everyone working with them. For most charities, COVID-19 has led to funding interruptions, increased demand for services and safety concerns, with many organizations being forced to make tough decisions.

But not all has been doom and gloom here at BTSNZ. During the pandemic, we began our online support group meetings that continue to be well attended post lockdown. Given the geographic nature of New Zealand and how our community is spread out, in many ways, this works better than meeting in person.

From an acorn of an idea BTSNZ has become New Zealand's leading brain tumour support charity. Whatever the situation, BTSNZ will continue to provide information, support and guidance to brain tumour sufferers, their families and friends, whilst advocating for first-class treatments, care and support to ensure the best possible outcomes and quality of life. ■

For more information, please go to www.braintumoursupport.org.nz




Cure Brain Cancer Foundation is the leading voice for brain cancer research, advocacy and awareness in Australia. We strive to rapidly increase brain cancer survival and improve the quality of life for people living with this disease – it's at the core of everything we do.

Our Vision
A cure for brain cancer.

Our Mission
Unite our community to increase brain cancer survival & quality of life.

curebraincancer.org.au

You can bring hope to the 27 Canadians diagnosed with a brain tumour every day


...and, you can do it **YOUR WAY!**



YOUR WAY TO
#EndBrainTumours

Together, we will provide hope,
Together, we will #EndBrainTumours!

www.endbraintumours.ca

EVERY BRAIN deserves a FUTURE.

Join the Pediatric Brain Tumor Foundation in our mission to **Care. Cure. Thrive.** and give kids diagnosed with brain cancer a chance to reach for their dreams, instead of fight for their lives.

CARE. PBTF is a critical point of care for families, empowering them with information, financial relief, and emotional support.

CURE. PBTF provides leadership and funding to accelerate the discovery of targeted therapies for kids battling brain tumors today.

THRIVE. PBTF offers families a thriving community of peers and supporters who walk beside them from diagnosis through treatment and beyond.

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Jessica Morris
Founder, OurBrainBank
1963-2021

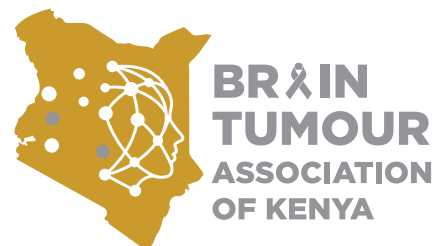
Keeping Jessica's vision alive to move glioblastoma from terminal to treatable, powered by patients



OurBrainBank OurBrainBank.org

BTAK: The establishment of the Brain Tumour Association of Kenya

Trizah Tracey John (MBChB, MMed-Neurosurgery), Deputy Secretary General
Brain Tumour Association of Kenya (BTAK)



Introduction

The Brain Tumour Association of Kenya (BTAK) is a non-profit organization registered in Kenya in accordance with the Kenya Societies Act. BTAK was established in 2021 by neuro-oncology healthcare professionals comprising a neuro-oncologist, a neuropathologist and neurosurgeons. The main purpose of establishing BTAK is to support brain tumour patients and caregivers through advocacy, promotion of quality healthcare, dissemination of information and creation of awareness of brain tumours.

Background

The cancer burden has been rising globally, exerting significant pressure on populations and health systems. The United Nations Sustainable Development Goals call for a reduction by one-third of premature mortality from non-communicable diseases (NCDs), including cancer.

In Kenya, cancer is the third leading cause of death after infectious and cardiovascular diseases. Brain tumours are the commonest cause of tumour-related deaths in children. Cancer prevention and control requires a health-systems approach that includes the entire continuum of care: prevention, early detection, treatment,



Brain Tumour Association of Kenya (BTAK) officials (left to right, back row: Dr. P Minda Okemwa, Dr. Michael AA. Magoha, Dr. Vincent D. Wekesa; seated: Dr. Trizah Tracey John; not pictured: Dr. Nilesh Mohan)

palliative care, survivorship, monitoring, evaluation and research.

The Kenyan Constitution (2010, Article 43) grants every person the right to the highest attainable standard of health, which includes the right to health care for brain tumour patients.

Landscape of care for brain tumour patients in Kenya

Kenya has made significant strides

in upscaling the quality of healthcare delivered to brain tumour patients. The National Cancer Control Strategy is currently in place and under implementation. Infrastructure development and expansion as well as equipment acquisition is ongoing. Some training programs for neuro-oncology professionals are in place aimed at increasing the number of health care workers.

Despite the tremendous efforts and achievements so far, there still exist significant gaps in the care received by brain tumour patients.

In terms of infrastructure in Kenya, there are only two public neurosurgical centers in the country against a population of approximately 50 million persons. These centers are located in Kenyatta National Hospital and Moi Teaching and Referral Hospital, in Nairobi and Uasin Gishu counties respectively. Out of 47 counties, 45 counties do not have a neuro-oncology center. The country has inadequate diagnostic and treatment equipment. In addition, neuro-oncology human resource for health is lean and not

well distributed in the country; the teams are poorly coordinated. The financial expenditure by government on brain tumours is inadequate and the country lacks dedicated policies to guide care for brain tumour patients. Coverage for health insurance is low. Availability of data, information and technology is inadequate and not well organized. Research on brain tumours including therapies and diagnostics, lags behind. In addition, there is low awareness of brain tumour prevention and control in the population. These and other challenges may result in poor outcomes in neuro-oncology.

As a result of the existing gaps, brain tumour patients in Kenya are faced with

a myriad of challenges. Most patients and caregivers travel long distances to access neuro-oncology care. In addition, patients wait for long periods of time to undergo elective surgeries, the cost of treatment is prohibitive, and most patients pay out-of-pocket for care. These and other challenges lead to late diagnosis, delayed and inadequate treatment for patients, psychological and emotional trauma for patients and their caregivers, and may eventually result in poor outcomes in neuro-oncology care.

It is this background of challenges that informed the establishment of BTAK as one way of dealing with the issues, through collaboration and partnerships with the relevant stakeholders. ■

BTAK Officials



Chairperson: Dr. P. Minda Okemwa (MBChB, MMed-Pathology, Neuropathology) Consultant Pathologist/ Neuropathologist, Lecturer, Head of Anatomic Pathology, University of Nairobi, Kenyatta National Hospital. Dr Okemwa is passionate about diagnostics and research especially on brain tumour prevention and control in the population.



Deputy-Chairperson: Dr. Vincent D. Wekesa (MBChB, MMed-Neurosurgery, Fellowship: Base of skull & Cerebrovascular). Consultant Neurosurgeon, Dr Wekesa is a Lecturer based at the Department of Surgery, the University of Nairobi, Kenyatta National Hospital. He is zealous about the management of complex brain tumours and research.



Secretary General: Dr. Michael AA. Magoha (MBChB, MMed-Neurosurgery). Dr Magoha is a Consultant Neurosurgeon and Lecturer based at the Department of Surgery, the University of Nairobi and Kenyatta National Hospital. He has a keen interest in management, education, and standards of care for brain tumour patients.

continued ►



Deputy Secretary General: Dr. Trizah Tracey John (MBChB, MMed-Neurosurgery), Consultant Neurosurgeon, Deputy Director of Medical Services Ministry of Health, Honorary Lecturer at the University of Nairobi, Kenyatta National Hospital. Dr. John is also trained in Health Systems Management and Strategic Leadership and is currently pursuing an MBA-International Healthcare Management at the University of Cumbria (RKC). Dr. Tracey is passionate about improving overall quality of healthcare in Kenya, more so for brain tumour patients. She is the author of the book "Guidelines for Early Diagnosis of Childhood Brain Tumors in Kenya" published in April 2021. Dr. Tracey has conducted research on delayed diagnosis of brain tumours in Kenya. She is also the Secretary General of the East African Association of Neurological Surgeons (EAANS).

BTAK Advisory Board



Dr. Scott L. Coven (DO, MPH, Fellowships: Pediatric Hematology /Oncology, Neuro-Oncology) Medical Director, Comprehensive Pediatric Neuro-Oncology Program at Riley Hospital for Children at Indiana University Health; Assistant Professor of Pediatrics, Pediatric Hematology/Oncology Department of Pediatrics at Indiana University and Riley Hospital for Children. Dr. Coven is active in promoting awareness of brain tumours in children, as well as expanding expertise in pediatric neuro-oncology services in Kenya.



Professor Nimrod J. M. Mwangombe (MBChB, MMedSurg, PhD, FCS, FAANS, MKNAS) Currently a Consultant Neurosurgeon, Professor of Surgery, Kenyatta University. Over 40 years of experience in neurosurgery at the Department of Surgery, University of Nairobi/Kenyatta National Hospital. Founding member and coordinator of the University of Nairobi Mmed-Neurosurgery program. Passionate about research and education in neurosurgery. President, Pan African Association of Neurological Sciences (PAANS). Founder and patron of East African Association of Neurological Surgeons (EAANS).

BTAK Vision:

To have a country where all brain tumour patients receive quality healthcare; patients and caregivers are well informed and supported.

Mission:

The mission of BTAK is to promote delivery of quality healthcare for brain tumour patients in Kenya. BTAK also aims to provide information, support and to advocate for brain tumour patients and their caregivers.

Tagline:

United to fight brain tumours.

Pillars

1. To promote quality, accessible, and affordable healthcare for brain tumour patients.
2. To engage in advocacy, creation of awareness and dissemination of information on brain tumours.
3. To support research, education, and innovation in the management of brain tumours.

Achievements so far:

1. BTAK has established a Neuro-Oncology Multi-disciplinary team (MDT) that meets bi-monthly to discuss the management of brain tumour patients with a view to achieving the best practice
2. A brain tumour registry has been established in Kenyatta National Hospital using the REDCap system
3. Identified a new book for the purposes of creating awareness

Plans for the year:

BTAK has outlined priority activities for the year that include but are not limited to:

1. Creation of awareness on brain tumours in Kenya
2. Establishment of a central brain tumour registry in Kenya
3. To conduct an annual scientific conference

References:

1. health.go.ke/wp-content/uploads/2017/07/kenya-national-cancer-control-strategy-2017-2022.pdf
2. Kenya cancer policy 2019 new.cdr (health.go.ke)
3. Guidelines for early diagnosis of childhood brain tumours in Kenya / 978-620-3-85589-0 / 4.9786203855890 / 6203855898 (lap-publishing.com)
4. Development of guidelines for early diagnosis of childhood brain tumours at Kenyatta National Hospital (uonbi.ac.ke)



Treasurer: Dr. Nilesh Mohan (MBChB, MMed-Neurosurgery, Fellowship: Neuro-Oncology & Skull base) Consultant Neurosurgeon based at Moi Teaching and Referral Hospital. He is also the Treasurer of the East African Association of Neurological Surgeons (EAANS). Dr. Mohan is passionate about research and quality care for brain tumour patients.

The Kenyan Constitution (2010, Article 43) grants every person the right to the highest attainable standard of health, which includes the right to health care for brain tumour patients.

Data-driven efficiency across the cancer care pathway

Shannon Boldon and Suzanne Wait
The Health Policy Partnership on behalf of All.Can International

About All.Can International

All.Can International is a multi-stakeholder, not-for-profit organisation (ASBL) registered in Belgium, that aims to identify ways in which resources in cancer care can be used more efficiently, with the goal of achieving better patient outcomes. The International Brain Tumour Alliance (IBTA) is a founding member. On 27 May 2021, All.Can published a landmark new report: *Harnessing data for better cancer care*, assessing how the power of data can be optimised to enable better and more efficient cancer care. This article presents an overview of the findings. The full report is publicly available on the All.Can website (www.all-can.org).



Changing cancer care together

The power of data to transform cancer care

Cancer care is advancing at a speed never before seen, and data are at the core of many of these advances. Data are the foundation of a learning healthcare system – enabling improvements in both efficiency and quality of cancer care across the entire care pathway.

The amount of data we now have at our disposal is considerable – as well as the insights we can draw from it. Mobile applications and smart devices now enable the collection of health data in a person's daily life outside of clinical settings, allowing for remote monitoring and identifying critical health events sooner. Different sources of data can be combined and analysed thanks to machine learning, artificial intelligence and improved processing speeds never seen before. The result is that we are now able to solve some of the most complex challenges in healthcare at a scale and speed that were previously impossible.

Many of these advances could be transformational to the future of cancer care (including care for brain tumour patients) if

applied at scale, creating greater efficiency as well as improved outcomes for patients.

We are still far from fully harnessing the potential of data to transform cancer care

Challenges inherent in data	Challenges with data systems	Challenges to embedding data into clinical practice	Challenges in drawing insights from data
Poor data quality	Data siloes hindering the ability to link data across different data systems	Data that cannot be actioned or that have limited use in guiding cancer care	Inadequate analytical methodologies, poorly validated artificial intelligence algorithms and inherent biases with data analysis
Data not representative of the entire population (inequity and bias)	Limited interoperability, further hampering data linkage	Poor integration of data insights into clinical decision-making	Poor timeliness, relevance and granularity of data, limiting multi-stakeholder use
Lack of data reflecting the patient perspective and outcomes that matter most to individuals	Inconsistent use of data governance frameworks	Low patient trust in appropriate use of their health data or privacy protection	Limited use of data to drive value-based healthcare at scale
		High burden of data collection, leading to limited buy-in from healthcare professionals	

Table 1. Challenges to achieving the optimal use of data in cancer care

Despite their enormous promise, several hurdles hinder our ability to fully harness data to their full potential. Many of the advances mentioned above are still at early stages of implementation, and the notion of 'data rich, information poor' rings true in cancer care. Persisting challenges remain in the quality of data, the systems used to collect them, integrating data into clinical care and using data to draw meaningful insights to drive change. These challenges are presented in Table 1, and some of the most pressing challenges are summarised below.

a. Data are not always representative of entire populations (inequity and bias)

Inequities in data can take several forms, introducing biases in the availability of data about certain populations defined by race, ethnicity or socioeconomic status, as well as varying amounts of data available for different types of cancer, including brain tumours.

Current data equity challenges mean that not all people benefit equally from data innovations in cancer care – with traditionally, data collection favouring Western and Caucasian populations. Without data specific to given populations, it is difficult to know the impact of cancer or health interventions on those groups.

Data can also be biased towards different types of cancer. For example, most cancer registries do not collect data on cancer recurrence, therefore information is particularly scarce on people with metastatic cancers. Similarly, lack of available data on some rare cancers like brain and CNS tumours has traditionally resulted in limited research opportunities or innovations for these conditions, leading to fewer treatment options for patients.

Policymakers can help create greater equity in data collection by:

- Demanding greater equity in cancer research and care by ensuring appropriate representation of people of different races and ethnicities, sex and cancer types in cancer data sets.
- Holding institutions accountable for providing equitable cancer care by capturing performance on key quality indicators according to patients' race, ethnicity, sex and socioeconomic status.
- Ensuring proportionate allocation of funds towards specialist cancer registries to collect data on different populations of cancer patients for whom data are less available.

b. We lack data reflecting the patient perspective and outcomes that matter most to them

Patient-generated health data, such as patient-reported outcomes measures and patient-reported experience measures, are vital to our understanding of the patient's perspective on quality and impact of their

care. Yet these data are still not always collected as part of routine care.

Even when they are collected, patient-reported data are not always used to guide patient care. As a result, we miss opportunities to make each person's care more patient-centred, and to gain a complete picture of how healthcare systems are performing from the point of view of the people they are designed to serve.

To create more patient-centred data collection, policymakers should focus on:

- Encouraging systematic and standardised collection of patient-generated health data, such as measures of patient-reported outcomes and patient-reported experiences, in key national health data sets.
- Including these data in regular monitoring and performance evaluations of cancer care to guide improvements most relevant to patients.

c. Patients may not always trust that their data are being used appropriately and may have concerns over data privacy

It is important to never lose sight of the fact that people whose data are being collected have a right to know how their data are being used. Public opinion research shows a willingness from both patients and the general public to share personal health data for research purposes, but on the condition that it is done securely, and that data are accessible only by authorised parties. Each person should know the goals of research involving their data, and how they can opt out. Fostering transparency in data use across cancer care helps to build public trust in data collection efforts. Continued conversations, education and an open dialogue with patients and the general public are important to ensure their data privacy and confidentiality concerns are being addressed.

To build patient trust and protect patient interests in data sharing, policymakers should focus on:

- Creating public awareness and education campaigns to convey the power of meaningful data to better manage cancer care.
- Engaging with patients and patient representatives to discuss how

data are being used, and address misconceptions around the nefarious use of health data.

- Continuously adapt legislation and tools to give citizens appropriate control over their own health data, so they may act as their own data 'gatekeepers'.

The way forward

The potential of data to improve cancer care is considerable – but it will only be achieved if we overcome existing challenges to their collection and use. Having the correct data systems in place and being able to harness their value is as important to the future of cancer care as new medicines and other advances. It is also integral to ensuring the sustainability of health systems and delivering better care for patients. These goals are especially pertinent in the context of the COVID-19 pandemic and health system recovery.

The newly launched All.Can report *Harnessing data for better cancer care* hopes to offer solutions and a useful starting point to drive change and move the needle in optimising the use of data in cancer for the benefit of all cancer patients, including those diagnosed with brain tumours. ■

All.Can International's work is made possible with financial support from Bristol Myers Squibb (main sponsor), Roche (major sponsor), MSD and Johnson & Johnson (sponsors), Baxter and Illumina (contributors), with additional non-financial (in kind) support from Helsys, The Health Value Alliance and Goings-On. In addition, this report received financial support from Novartis.

For further information:

All.Can Secretariat Contact: Nazli Guel Uysal, NazliGuel.Uysal@interelgroup.com
All.Can Data Report Contact: Shannon Boldon, shannon.boldon@hpolicy.com

Gemeinsam gegen Glioblastom - Together against Glioblastoma

A German initiative to bring together glioblastoma patients, caregivers and experts



Prof. Dr. Martin Glas, 1st Chairman of Deutsches Innovationsbündnis Krebs & Gehirn e.V. (DIK&G) and Head of the Neurooncology Center at the West German Cancer Center and Division of Clinical Neurooncology, Dept. of Neurology, University Hospital Essen, Germany



Patients suffering from malignant brain tumours face a difficult road ahead: the diagnosis can be very overwhelming, and patients can quickly feel lost facing this life-altering reality. This can be particularly daunting for those suffering from glioblastoma, an aggressive brain tumour affecting 24,000 new patients in Europe every year.

Searching for information online often worsens the situation. Not only is it difficult to find reliable information, but the medical jargon adds another obstacle to patients' ability to understand, especially those who have never heard of glioblastoma prior to receiving their diagnosis. On top of this, patients and caregivers reported the feeling of isolation – they often feel they are alone in fighting the illness.



Prof. Dr. Frank Giordano, 2nd Chairman of Deutsches Innovationsbündnis Krebs & Gehirn e.V. (DIK&G) and Director of the Clinic for Radiotherapy and Radiooncology at the University Hospital Bonn, Germany



The German campaign Gemeinsam gegen Glioblastom (Together against Glioblastoma) aims to address these two pressing issues by bringing patients, caregivers and renowned brain tumour specialists together. In digital gatherings and via social media, specialists provide verified information and answer patients' and caregivers' questions, thereby creating an engaged online community.

About Deutsches Innovationsbündnis Krebs & Gehirn e.V.

The campaign was founded in June 2020 by the Deutsches Innovationsbündnis Krebs & Gehirn e.V. (DIK&G; German Innovation Alliance for Cancer & Brain) and the patient advocacy group yeswecan!cer.

The DIK&G is an association of physicians,



Jochen Kröhne, Media entrepreneur and Managing Director of yeswecan!cer



scientists, patients, caregivers, companies, people in public life, celebrities and influencers which raises awareness of brain tumour patients' needs and aims to provide sustainable improvement for patients' therapy and quality of life. With their mission "change for good", the organisation advocates for more transparency and cooperation amongst all interest groups, including the healthcare industry, and aims to enable an open dialogue.

Gemeinsam gegen Glioblastom – providing answers

Another important focus area for DIK&G is the digitization of medicine: how can patients and caregivers benefit from the increasing number of digital offers to better manage the disease together with their physicians? Gemeinsam

gegen Glioblastom aims to be one of many possible answers to this question, by providing easy access to scientific information, but also by enabling the formation of a community of patients and caregivers no matter where they are located in Germany, Austria or Switzerland. As Prof. Martin Glas, Chairman of the DIK&G and co-founder of Gemeinsam gegen Glioblastom, emphasizes: "Over the last years, diagnosis and treatment options have improved significantly, but there is little awareness of the progress that has been made. The goal of the campaign is to give patients access to this information in a way that is easy to understand for them and hopefully makes their experience with the disease a little less overwhelming, less isolating."

Given the malignancy and short life expectancy of patients with glioblastoma, it is almost always necessary for patients to undergo treatment right away, after which some will suffer from side effects or neurological restrictions. This makes digitization even more crucial, as traveling to meet other patients or gathering the strength to form a patients' advocacy group are oftentimes tasks too burdensome to achieve.

Yes we can with yeswecan!cer

Yeswecan!cer, the co-founding organisation of Gemeinsam gegen Glioblastom, is all too aware of these issues. That's why the non-profit organisation has founded the YESIAPP that serves as a safe digital space for all cancer patients to connect and share experiences. Since its genesis, yeswecan!cer has not only built a substantial community, it also works with renowned cancer specialists and holds large annual events bringing patients and caregivers together. Jochen Kröhne, managing director of yeswecan!cer, knows glioblastoma patients differ from breast cancer or prostate cancer patients – they are less in number, and often don't know where to turn to following their diagnosis. Gemeinsam gegen Glioblastom supports patients in this trying time and complements yeswecan!cer's digital offers by staying true to their mission: to commit to open, authentic and positive communication for and amongst patients.

Bringing hope and reliable information to brain tumour patients

Gemeinsam gegen Glioblastom cooperates with experts in Germany, Austria and Switzerland. At the core of the campaign is the

website www.gemeinsamgegenglioblastom.eu that serves as an information hub for those seeking verified information on the disease. What is unique about the campaign's website is that patients and caregivers can directly address experts with their questions. Since the start of the campaign, hundreds of questions have been sent in on topics such as the provenance and heredity of glioblastoma, promising new studies and treatment options and individualized medical treatment for the disease. Moreover, the website provides information on treatment options, useful checklists for patients and news from the glioblastoma community.

While it is pivotal for patients to be educated about their disease in a comprehensible and trustworthy manner, it can also be helpful to connect with others as a way of coping. That's why the campaign website also showcases the stories of glioblastoma patients and their caregivers in the form of short videos, talking about their experience and how they live their everyday lives with the disease.

As one patient says in his video available on the website: "Life doesn't stop with the diagnosis. It can't stop, otherwise the damn tumour wins. And we can't let that happen."

With these stories, the campaign hopes to help others to live their lives as best they can despite the diagnosis. The campaign's Facebook and Instagram handles serve as additional platforms for patients and caregivers to ask each other questions, share their struggles and give tips – in short, create a sense of community to minimize the feeling of isolation. Yeswecan!cer's motto is "you are not alone", and as Gemeinsam gegen Glioblastom has shown over the past months, nobody is in fact alone even with a glioblastoma.

One of the highlights of Gemeinsam gegen Glioblastom is the annual virtual event on the occasion of Glioblastoma Awareness Day. This commemorative day is held on the third Wednesday of July but due to prior scheduling, it was held in Germany on July 17th this year and for the second consecutive time, the event was hosted via Zoom to enable patients from all over Germany, Austria and Switzerland to easily attend despite the pandemic. As in the previous year, numerous renowned experts such as Prof. Martin Glas and Prof. Frank Giordano, Chairmen of DIK&G and brain tumour specialists Professor Roger Stupp (Chief of Neuro-oncology in the

Department of Neurology at the Feinberg School of Medicine at Northwestern University in Chicago, USA) and Christian Freyschlag MD (Director of Neuro-oncology at the Neurosurgery Clinic of the University Hospital Innsbruck, Switzerland) discussed a variety of topics ranging from the treatment of glioblastoma, to new promising studies, to advances in the field of digitization that may benefit brain tumour patients in the future.

Those interested in this German-language event can find further information on the website www.gemeinsamgegenglioblastom.eu where the recordings of the event are available.

A growing movement...

To strengthen the international glioblastoma community, Gemeinsam gegen Glioblastom actively aims to share information and resources with partners in non-German-language countries. A first step towards international collaboration has been made earlier this year, when Gemeinsam gegen Glioblastom and its founders DIK&G and yeswecan!cer translated *The Brain Tumour Patients' Charter of Rights* initiated by the International Brain Tumour Alliance (IBTA) into German and gladly presented this important living document to the campaign's community. ■

If you have been diagnosed with a glioblastoma, or are the relative of a glioblastoma patient, remember that you are not alone – and if it is accessible to you, visit www.gemeinsamgegenglioblastom.eu (German language website) for more information on this brain tumour, for interviews with patients, caregivers and experts, and for a comprehensive FAQ on the disease.

The yearly Glioblastoma Day event hosted by Gemeinsam gegen Glioblastom took place on July 17th 2021. All recordings of the event are available on the campaign's website www.gemeinsamgegenglioblastom.eu as well as on the YouTube channel Gemeinsam gegen Glioblastom (German language only). If you don't want to miss out on the next event, make sure to check the website regularly for any updates.

The multi-faceted work of Brain Tumour Ireland

Fiona Keegan, National Coordinator
Brain Tumour Ireland



Next year Brain Tumour Ireland will celebrate ten years supporting brain tumour patients, their families and carers. We have achieved a lot over those years and our brain tumour community has met the many challenges faced by brain tumour patients, including the Covid-19 pandemic, with extraordinary resilience. We look forward to celebrating all we have achieved together over the past ten years and in the meantime, we are delighted to share some of our achievements here.

Paediatric Support

Over the last year, we at Brain Tumour Ireland have expanded our remit into the area of paediatric information and support. Approximately 50 children a year are diagnosed with a brain tumour in Ireland. There are limited supports available for parents of these children and Brain Tumour Ireland is endeavouring to provide that support.

In 2020 our Awareness Week campaign focused on raising awareness amongst the public of the incidence of paediatric brain tumours in Ireland. We launched

a new paediatric website as part of the campaign and we sought to let families of a child who has had a brain tumour diagnosis know that we are here to support them and their children.

In addition, we held a number of online events for parents and the medical profession covering topics such as childhood bereavement, support for siblings, and taking care of yourself as a parent. We also hosted a session of fun and games for children with a brain tumour diagnosis and their siblings and we finished the week with our most successful 'Wear A Hat Day' fundraiser yet.

We are enormously grateful to all the children and their families for their continuing support and to the medical profession who provide such wonderful care on a daily basis. We continue to work with our colleagues in the main

paediatric centres in Ireland to ensure that all rehabilitation services available to children with an acquired brain injury are fully inclusive of children with a brain tumour diagnosis. Please go to <https://braintumourireland.com/paediatric/> to find out more.

Wellness Through Music

In response to all of our front-facing services having to close in early 2020 because of the COVID-19 pandemic, like so many others we decided to move our support services online. This presented some challenges; however, it has also led to the breaking down of geographical barriers and allowed us to connect with so many more people throughout the country.

As part of our online programmes, we received a very kind offer from Jess O'Donoghue to facilitate a series of virtual



Brain Tumour Ireland has expanded its remit into the area of paediatric information and support to help benefit families like the Gaughrans. Pictured, left to right, is Mum Cliona Gaughran, four-year-old Izzy Gaughran, grandmother Margaret Gaughran and six-year-old Ben Gaughran

music therapy and relaxation sessions for our brain tumour patients. Jess is a speech and language therapist and holds a master of arts in music therapy. She primarily works with children and adolescents who have experienced developmental stuttering. The music therapy sessions, which are held once a month, are a lovely mixture of social chat and guided relaxation to music. These

sessions have become an important part of our brain tumour community's calendar and the feedback from participants has been wonderful. We are immensely grateful to Jess for providing these Wellness Through Music sessions for our brain tumour patients for free.

Brain Tumour Tissue Biobank

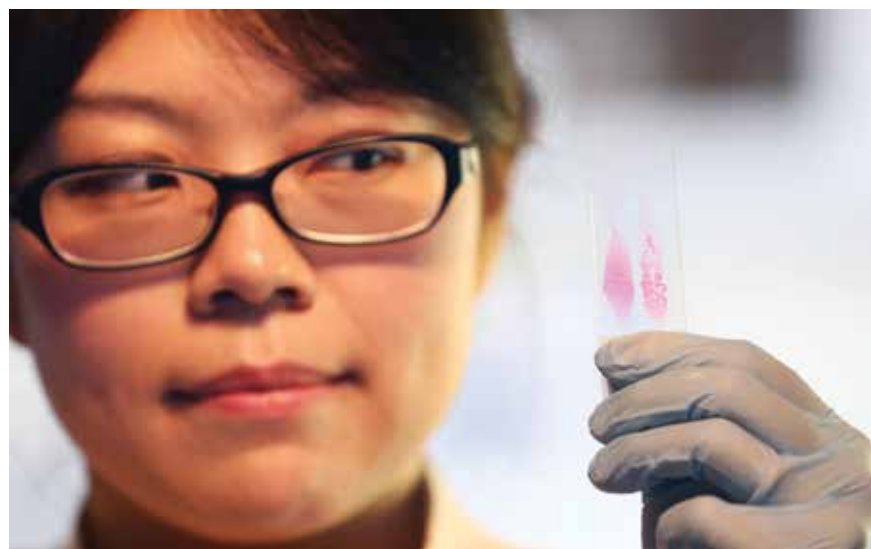
Brain Tumour Ireland recognises the importance of research in securing better outcomes for brain tumour patients. It is so important for our fundraisers to see that we are using funds raised by them to support the advancement of new treatment options, particularly in the area of glioblastoma (GBM). Brain Tumour Ireland is proud to part-fund Ireland's first dedicated brain tumour biobank in partnership with the Royal College of Surgeons in Ireland and Beaumont Hospital. This is the first biobank of its type in Ireland and one of only a small handful that exist in Europe.

A biobank is a large collection of biological, medical data and tissue samples, collected for research and diagnostic purposes. A patient who is having brain surgery as part of their clinical treatment will have the tumour removed, examined and diagnosed. Following this, the excess brain tissue which has been removed during surgery will be stored in the biobank. All samples included in the biobank are anonymised and the patient's consent is sought in advance of treatment.

Based at Beaumont Hospital in Dublin, the brain tumour biobank is a repository for brain tumour samples which will enable researchers to use samples for future clinical studies, to identify and diagnose tumours in other patients and to help develop cancer treatments.

In an exciting development, the biobank is now supporting a major new study on glioblastoma (GBM). Professor Annette Byrne from RCSI is leading an international team of scientists on a major research study that aims to train the next generation of brain cancer researchers.

continued ➤



Dr. Daphne SY Chen, Neuropathology Department, Beaumont Hospital brain tumour tissue biobank, Dublin, Ireland



Left: Cliona and Izzy Gaughran

The project - "GLIOTRAIN"- has received funding of almost €3.9 million from the European Commission's Horizon 2020 Research and Innovation Framework Programme.

Brain Tumour Ireland is delighted that the brain tumour biobank will support this study. It is a really important development in brain tumour research here in Ireland and for the future development of novel therapeutics.

The existence of the biobank is, of course, thanks to the many people who donate to Brain Tumour Ireland and who organise fundraising events for us. We also wish to acknowledge the many patients who have consented to the donation of their tissue in order to help researchers find a cure for this terrible disease.

The Future

Brain Tumour Ireland has recently filled a number of vacancies on our Board of Directors, following the retirement of some of our members. The Board will be looking at a new three-year strategy that will help us to build on the work already done and to look at new ways of growing the services we can offer to brain tumour patients and their families.

We look forward to the challenge. ■

New Chairperson for BTI



Peter Cosgrove, new Chairperson of Brain Tumour Ireland

Peter Cosgrove joined Brain Tumour Ireland in February 2021 as Chair. Peter has worked with a number of Boards, currently serving as Vice Chair of the mental health charity Aware and Board member of the 30% Club which promotes gender diversity. He has

been the Chair of Junior Achievement Ireland, the President of the National Recruitment Federation of Ireland and the Chair of Blackrock Athletics Club, one of the largest athletic clubs in Ireland. Peter runs a future of work insights company, Futurewise, and has worked in the professional services arena in Ireland and the UK. He has written two books, *Fun Unplugged* and *Family Fun Unplugged* designed to support families in taking time off from their digital devices. Peter is married with two children and he himself comes from a traditional Irish family of nine children.

Peter said: "I'm very proud to join the Board of BTI which has been very impressively run and has made a huge impact for the awareness and support of brain tumours in Ireland. I hope, alongside a very impressive Board, we can maintain the great work and grow the charity further to offer even more for those in need." ■

Tokyo OT Brain Tumor Network

Mayumi Horikawa of the Tokyo OT Brain Tumor Network wrote to us to say that a virtual multidisciplinary meeting of brain tumour professionals was held on 21st November 2020. The Network began when three occupational therapists (OTs) in Tokyo began exchanging information about brain tumors. They formally established their group - the Tokyo OT Brain Tumor Network - in 2016. In addition to occupational therapists, the Network also comprises nurses and physiotherapists. Information is provided by the Network and includes such topics as the perioperative period for brain tumour patients, outcomes, school, employment, chemotherapy, radiation therapy, the

adolescent and young adult (AYA) population of brain tumour patients, elderly people diagnosed with brain tumours, nursing and nutrition.

In addition, the Tokyo OT Brain Tumor Network is studying the ideal approaches to patient support in cooperation with the non-profit organisation, the Japan Brain Tumor

Alliance (JBTA). The main activities are (1) study session, (2) research, writing, (3) providing information to patients and their families, and (4) enlightenment activities. Currently, the JBTA is creating question and answer (Q&A) leaflets for brain tumour patients and their families. ■



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**

Rare Cancers Europe

Rare Cancers Europe is a multi-stakeholder partnership, founded in 2008 and coordinated by the European Society for Medical Oncology (ESMO) that brings together scientific societies, patient and research organizations, healthcare and education providers and the industry.

RCE's mission is to place the issue of rare cancers firmly on the European policy agenda, to identify and promote appropriate solutions and to exchange best practices. Currently, the partnership is working towards the implementation of the recommendations of the Rare Cancer Agenda 2030, the EU Joint Action on Rare Cancers' overarching deliverable.

For more information, please visit 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;47:2493-501.

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A European Reference Network (ERN)
Helping patients with Rare Adult Solid Cancers

■ ■ EURACAN is a virtual Network gathering Health Care Providers with high expertise in the 10 rare cancers covered by EURACAN, including rare brain tumours and spinal cord. You can be referred to EURACAN, your doctor will remain your single point of contact, yet, he 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 also invest in joint research activities (ARCAGEN Project), organise trainings for healthcare professionals and work together on Clinical Practice Guidelines.

Clinical Practice Guidelines

- In collaboration with EANO, development and publication of clinical practice guidelines for diagnosis, treatment, and follow-up of post-pubertal and adult patients with medulloblastomas
- In collaboration with EANO and SNO development of guidelines on Neuroglial tumours as well as germinomas.

Registry STARTER Project

Implementation of a **clinical registry** for the ERN EURACAN to describe how rare cancers develop and progress, to evaluate factors that influence prognosis, to assess treatment effectiveness, to measure indicators of quality of care

November 2021
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This project is funded by the European Union

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*Gemeinsam gegen Glioblastom translates to Together against Glioblastoma



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From a handpainted original by a Brain Tumour Survivor



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The resilience of a brain tumor support group: before, during and after a pandemic

Karyn Schmidt APN and Jean Arzbaeher APN
Chicago, United States

The brain tumor support group at the Cancer Support Center in Homewood, a southwest suburb of Chicago, met for the first time in March 2010. Started by an advanced practice nurse (APN) together with a long term brain tumor survivor and his wife/caregiver, our group has developed with a tremendous feeling of responsibility to each other, respect, genuine caring and a great sense of humor.

Largely due to the impact of some early and influential group members, who demonstrated through words and actions what living with a brain tumor and not for a brain tumor really is, our members have become very close and our annual holiday party is like a family reunion with close to 100 people attending. We are a powerful presence in the fund-raising walk for the cancer center and our “Kiss my Astrocytoma” team, wearing neon green shirts, has won the award for the largest team for the past five years. Thus, the pandemic really hit us hard.

Monthly meetings, pre-pandemic

Prior to the pandemic, we would start our monthly meeting as a full group, averaging about 20-25 participants, to share updates about recent events, family celebrations, good scans, bad news about scans, and discuss treatments. We would welcome any new members, always with someone in our group - without being prompted - choosing to sit next to the new member to make sure they felt welcomed. Our large group would then break into three sub-groups; survivors, caregivers, and “loves lost,” former caregivers who were active in the group whose loved one passed away. Each of these sub-groups had a facilitator, either an advanced



Karyn Schmidt

practice nurse or a cancer therapist. The sub-groups allowed for each group to process common concerns, share community and feel the support of those who are walking the same road with you, and often who have been where you are.

Suddenly...

On March 12, 2020, we had planned a pizza party to celebrate our support group's ten-year anniversary with over 100 people indicating they would attend. On March 11th, Covid-19 was declared a pandemic. Although stay-at-home orders had not yet been mandated, we made the difficult decision to cancel the celebration and suspend in-person meetings. Little did we know at the time that we would not meet again for 14 months!

The Cancer Support Center worked swiftly to establish remote support group meetings and in April we had our first virtual support group. We quickly learned that video meetings are just not the same. We still had good attendance and



Jean Arzbaeher

a mix of attendees, with new members joining intermittently. However, we noticed that the focus changed – it was more challenging to discuss difficult topics, because a physical presence makes a difference. It was harder to incorporate new members. At in-person meetings, one of our members would just park themselves on the chair next to the newcomer and help make the introduction to the whole group. Virtually, visitors who may have wanted to just “audit” the meeting found that we welcomed them boisterously and wanted to know all about them. There were a few occasions where they disappeared from the virtual group when someone tried to engage them in conversation. And our long-term bond showed – we know many of each other's stories and families and thus we caught up on social and support topics. It was supportive, but it wasn't always consistent with our prior support group vibe. We didn't break into sub-groups, so our caregivers didn't get to voice



It's a new world – the socially distanced meeting of the brain tumor support group at the Cancer Support Center in Homewood, Illinois, US

their concerns with other caregivers and our survivors didn't get to discuss their treatments, their hopes, their fears and everything in between.

We had members who passed away during this time. In the in-person group, our routine was to light a candle in honor of the member and then share our feelings about the loss. Often the caregiver of the person who passed away would attend so he or she could receive support from the group. Although we lit a virtual candle, the giving of support, hugs, and tears was sorely missed.

Context matters

On the positive side, remote meetings allowed us to stay connected and members who were not mobile enough to attend in-person groups previously could still participate. We were able to talk about our goals for the future, learn who was doing well and who could use some extra support. We could process together the personal experiences of COVID, medical care and well-being. We were able to move from being a regional group, with members from the Chicagoland area, to include more distant participants from around the country, who discovered the group online.

The consensus of the group was that we suffered from not being physically together, not being able to have the difficult

conversations and the happy celebrations, feeling the support that even just a physical presence can provide. We learned that context matters, especially when group members faced medical challenges, and that the flow of a video conversation feels very different from a conversation in person. Sometimes the technology slowed us down, but more than anything else, it was the actual physical separation that made the difference. Maureen Griffin, a ten-year brain tumor survivor, said it best when she said: “It was better than nothing. The year was so isolating that you needed something to grab onto while COVID was pushing us apart.”

The road back to normality


In May 2021, with vaccines readily available to all adults, and 30% of residents in the Chicagoland area fully vaccinated, the Cancer Support Center began to reopen for support groups. The brain tumor support group met in person for the first time in 14 months. Although attendance was small, with only seven people, it was great to be back! We offered the opportunity for people to continue to participate virtually, but there were no virtual attendees. The fellowship was re-established, and everyone verbalized how important it was to reconnect with others in the group.

Measures that the Cancer Support Center instituted to keep everyone

safe included mask-wearing, socially-distanced seating, and a limited number of attendees with RSVPs required. In general, we were a “hugging” group prior to the pandemic. Now, we give each other virtual hugs and elbow bumps instead. Members also commented on the fact that masks hide facial expressions, so it was important to show emotions through the eyes. Other measures that the cancer center instituted included installing a UV light in the furnaces with the purpose of killing the majority of viruses and adding air purifiers to each of the meeting rooms, as well as spacing apart the timing of programs to allow for adequate cleaning in between programs.

All in all, it felt good to be back to live support! The group showed its resilience by forging through the pandemic and doing the best that we could with the situation. We will continue to meet live but will also continue to offer a virtual option.

How the combination of virtual and live will affect the group is yet to be recognized. When the facilitators asked the group whether we should continue to meet, the overwhelming consensus was “of course.” Donna (a 15-year brain tumor survivor) and her husband Paul (caregiver) Vanryn said it best: “As long as brain tumors are still occurring, we need to be here to support anyone who is newly diagnosed or struggling.” ■




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GFME 20 years

GFME, Glioblastoma Fondation Michele Esnault, established in 2001 is a French-based (Marseille), patient-oriented, a support group involved in brain tumors. GFME translate and published 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 Paris, Brain Tumor Association For Research to rise funds. GFME is a website <https://gfme.fr>, a quarterly magazine, a phone assistance (33) 04.91.64.55.86, and a mailing-list mailing@gfme.fr. The group includes 700 patients, care givers, friends and family members around the globe. For more details gfme@free.fr



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PASNO membership is open to neurologists, neurosurgeons, medical & radiation oncologists, radiologists, nurses, students, and any healthcare provider interested in neuro-oncology.

K2 in Pakistan; considered the most difficult mountain to climb.

Multi-lingual brain tumour resources reflect Australia’s diverse population

Tricia Berman, Secretary and Public Officer of Brain Tumour Alliance Australia (BTAA) from 2015 to 2019

Australia has a multicultural population with 30 per cent of its people born overseas (2020, Australian Bureau of Statistics – ABS). In line with this high level of new diverse cultures, Brain Tumour Alliance Australia (BTAA) recognised a major gap in resources for non-English speaking brain tumour patients and their families. Research indicated that non-English speaking patients from culturally and linguistically diverse (CALD) backgrounds, relied on translators to interpret and advise them on their diagnosis and post-surgery requirements. Understandably, translators advised that they were not sufficiently knowledgeable about brain tumours to answer questions about procedures or to explain terminology used by the medical profession.



Tricia Berman

Three-year project to develop multilingual resources
BTAA applied for funding from Cancer Australia to develop new resources for brain tumour patients that helped them to better understand their medical journey. The information would be available in English and ten other languages. Funding was awarded in 2017 to achieve this through a *Supporting People with Brain Tumour project*. A Steering Committee (including some of Australia’s leading experts in brain tumour patient care and support) was established. An analysis of existing multinational brain tumour resources was undertaken and consultation began across Australia in 2017/18 with Australia’s brain tumour community. Non English-speaking patients and their communities were included. Two new resources - one on the brain

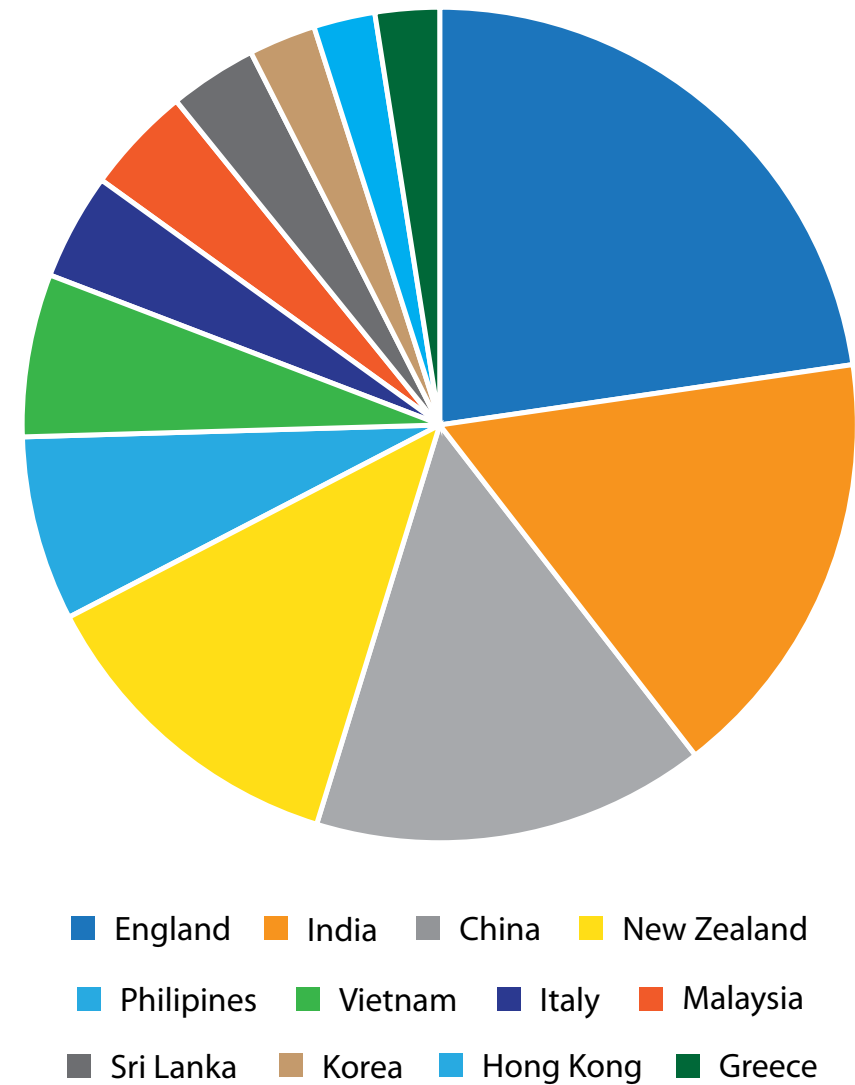
tumour journey and pathway, and the second on asking questions of healthcare professionals - were drafted and taken to the Queensland University of Technology’s Ethics Committee to ensure that they were appropriate for brain tumour patients, their families and carers. From mid 2018, the proposed new resources were discussed in patient workshops held across Australia, to seek feedback on their appropriateness. In May 2019 the two new resources were released nationally online, on the BTAA website and in events held in Sydney, Canberra, Melbourne, Hobart, Adelaide, Perth, Newcastle and Brisbane. The launch events were attended by patients, patient advocates, medical professionals and prominent doctors. A full programme included lectures from some of Australia’s leading experts in neurosurgery, neuro-oncology and radiation oncology. Copies of the resources were distributed to

the Australian medical profession for use on a day-to-day basis.

Resources translated into ten languages
The resources were released in the following ten languages as well as English in line with advice from multicultural organisations and Australia’s foreign-born population.

1. Arabic
2. Chinese - Simplified and Traditional
3. Dari
4. Filipino
5. Greek
6. Hindi
7. Italian
8. Vietnamese
9. Punjabi
10. Spanish

The multicultural resources
The first resource, *My Brain Tumour Pathway*, is a one-page document for brain tumour patients to record information about their brain tumour. It has the brain tumour journey shown diagrammatically on one side and the other side enables patients to record important information about their brain tumour. Patients can record their brain tumour type, their treating physician, their treatment plan and the contact names of those who will assist them. *My Brain Tumour Pathway* is in English and ten additional languages so that patients can record the information irrespective of their language capability. Patients can record their details with the assistance of their treating physician, surgeon and/or brain tumour nurse. The document is free on



A breakdown of the 30 per cent of people in Australia who were born overseas

the BTAA website and can be printed from the website. The second resource, *It’s Okay to Ask* (originally prepared by Dr Danette Langbecker and released in 2008 by the Queensland University of Technology) is to assist patients and their families to feel confident in asking questions of their treating physician about their brain tumour. The resource has been updated from its original 2008 version and also made available in ten languages in addition to English. This resource is a 36-page booklet which leads patients through seven specific areas of the brain tumour journey and helps patients to ask questions of their physician when diagnosed with a brain tumour. The areas covered are:

- **Diagnosis**
- **What you can expect in the future**
- **Symptoms and changes**
- **The healthcare team**
- **Support**
- **Treatment and management**
- **What to expect after treatment**

The important message of this resource is “Don’t be afraid to tell your doctor how much or how little you want to know.” There is space in the booklet for the patient, family member or carer to write the answers to questions. The resource can be read and printed online at the BTAA website in the language appropriate to the patient. BTAA also translated some existing videos into the same ten languages. “A

common path” suite of cancer support and advice videos was developed by NEMICS (The North Eastern Melbourne Integrated Cancer Service.) NEMICS, is a clinical network for people who have been newly diagnosed with cancer. As part of its project, BTAA translated the NEMICS video on ‘High Grade Glioma’ into ten languages and in the video three brain tumour patients speak about their journey following diagnosis.

A project that keeps helping
My Brain Tumour Pathway and *It’s Okay to Ask* are easy to read and powerful tools in helping brain tumour patients and their families to be more confident on their journeys. The BTAA project responded to a very real need in the Australian brain tumour community. It was possible because of help from neurosurgeons, brain tumour research, brain tumour patients, brain tumour hospital staff including nurses, non-English speaking community groups, and our country’s high level translation capabilities.

As a new member and Secretary of BTAA in 2016, leading the project and the journey was a privilege and most rewarding. The preparedness of medical and hospital staff, and brain tumour patients and families to give their time and expertise was simply outstanding. The support which the resources provide every day to brain tumour patients and their families is BTAA’s *raison d’être*. ■

For more information on multilingual resources provided by Brain Tumour Alliance Australia (BTAA), please visit <https://www.btaa.org.au/resources/languages>

Raise awareness of the challenges of brain tumours and plan an event for International Brain Tumour Awareness Week 2021 (30 October - 6 November)

Posterior Fossa Society - First Global Meeting

State of the art conference on cerebellar mutism / posterior fossa syndrome relevant to all professionals involved with the care of children and young people with brain tumours

Friday 9th to Sunday 11th September 2022, Liverpool Waterfront, UK

Professor Barry Pizer, Chair of the local organising committee of the Posterior Fossa Society's first global meeting
Liverpool, UK

Organised by the global Posterior Fossa Society, this conference will provide a state-of-the-art multidisciplinary update on cerebellar mutism syndrome (CMS), recognised as an often-severe, adverse effect of cerebellar injury as a result of surgery to the posterior fossa (lower part of the brain) and characterised by mutism (loss of speech) usually associated with rapid changes in emotions and moods..

The syndrome can occur in patients of any age but is more common in children where around 20 % undergoing posterior fossa surgery are affected. The core manifestations of CMS may be accompanied by a range of neurological issues such as cranial nerve palsies and other motor and sensory deficits. Affected individuals may have long-lasting neuropsychological impairments that include the Cerebellar Cognitive Affective Disorder. Whilst mutism recovers over time, a proportion of those affected will have prolonged speech deficits.

We promise you an amazing, not-to-be-missed, conference that will be a landmark event in the science and clinical practice of cerebellar mutism / posterior fossa syndrome. A number of world-leading speakers will present and we will welcome abstracts for both platform and poster presentation. Areas covered by the meeting will include the cause of CMS, preventative measures, advanced imaging, the function of the cerebellum, scoring



Professor Barry Pizer

systems, treatment (physical and drug therapy), and rehabilitation.

We are honoured that the meeting has come to Liverpool; a vibrant city with a rich maritime, art and musical heritage - one of the most visited cities in the United Kingdom. We are very proud of our city as a centre of research and learning with a proven track record of hosting major national and international congresses.

The venue for the conference is the Hilton Liverpool City Centre Hotel set on a delightful waterfront that has achieved world heritage status. We will offer a memorable networking and social program with the main networking event on the world-famous ferry across the River Mersey. As well as the conference hotel,

a full range of hotels can be booked, all of which are within walking distance, Together we will create an incredible meeting. ■

For further details, please visit the meeting website at www.delegate-reg.co.uk/pfs2022

For more information about the work of the Posterior Fossa Society, please visit www.posteriorfossasociety.org

A video on cerebellar mutism syndrome can be found here: <https://jtv cancersupport.com/collections/cerebellar-mutism/>

The IBTA maintains a list of neuro-oncology and relevant cancer conferences on its website at www.theibta.org



First Global Meeting

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www.posteriorfossasociety.org



– an Integrated Platform for Developing Brain Cancer Diagnostic Techniques

Erik R. Samuelsson, PhD student and Marie-Curie Early Stage Research Fellow
Science for Life Laboratory, Stockholm University, Sweden

An Integrated Platform for Developing Brain Cancer Diagnostic Techniques (AiPBAND) is a research program designed to train a new generation of entrepreneurial and innovative early-stage researchers (ESRs) to develop new biosensing techniques and diagnostic systems for early diagnosis of brain tumors using molecular biomarkers for brain cancer.

AiPBAND focuses on glioblastoma multiforme (GBM), a category of devastating and progressive brain tumors affecting around 25,000 people each year in Europe and responsible for most deaths from primary brain tumors. Currently, GBM is diagnosed via neuroimaging, such as computer tomography (CT), magnetic resonance imaging (MRI), and positron emission tomography (PET).

Refined diagnosis requires surgical biopsy for histopathological classification and grading. Despite extensive studies in the field, to date, there are no clinically validated biomarkers for reliable diagnosis and grading of this group of malignant diseases.

To address this need, fourteen ESRs from around the world are applying state-of-the-art technologies in parallel to 1) identify novel biomarkers from patients with GBM, 2) design multiplex biosensors to detect said biomarkers, 3) develop an extensive data-empowered intelligent data management infrastructure analysis, and 4) develop cloud-based diagnostic systems.

The ESRs are being trained by experts in ten academic and three non-academic

beneficiaries, belonging to five European Union member states and six partner organizations, ranging from neuroscience and engineering (including big data science) and healthcare to economics.

For more information on the partners, ESRs, and publications of AiPBAND, please visit: www.aipband-itn.eu or follow them on Twitter (@aipband_itn), Facebook (@aipband_itn) or LinkedIn(AiPBAND MSCA-ITN-ETN). ■

This project has received funding from the European Union's Horizon 2020 Research and Innovation program under the Marie Skłodowska-Curie grant number 764281.



Meagan's HUG Hero Julian Pope, on the stage at Meagan's HUG

Meagan's HUG - hope changes everything!

Elizabeth Becker
Meagan's HUG, Toronto, Canada



Christmas 2000 at the Hospital for Sick Children (SickKids) in Toronto, Canada. The Bebenek family learn of their daughter Meagan's diagnosis: an inoperable malignant brain tumour called a brain stem glioma. Meagan was four years old, the youngest of three children.

And so began Meagan and her family's journey: radiation treatments, meal drop-offs from the community, neighbours taking the older Bebenek children to their usual activities. Unanticipated life changes. But Meagan lived just as before, serene and generous, with a child's innocence and accepting way.

On Father's Day 2001, only a few weeks past her fifth birthday, and surrounded by her family, Meagan died. Leaving the hospital that day, leaving Meagan behind, Denise, Meagan's mother, asked her dad to stop the car. She lowered her car window and reached her arms out, longing to hold on.

A circle of hope

Denise dreamed of joining hands with others in a human "hug", a circle of hope that stretched around SickKids. Impelled by her own loss and vision, Denise founded Meagan's Walk: Creating a Circle of Hope, now Meagan's HUG. The first "hug" took place less than a year later, on Mother's Day, 2002.

Jay and Cindi Harding were there. Cindi's son, Cosimo, age 11, had died a year earlier, shortly before Meagan, and 18 months following the diagnosis of



Denise Bebenek (back row, centre), founder of Meagan's HUG, on stage at a Meagan's HUG event with Dr Eric Bouffet (far left), Dr Cynthia Hawkins (back row, far right) and Meagan's HUG Heroes and supporters. Photo by Fenton Mah

medulloblastoma. Cindi said: "Standing outside the hospital in the rain, I remember seeing Cosimo's oncologist, and feeling filled with emotion. I knew I could not go into the hospital. Cosimo kept me strong."

For twenty years, the Harding family has remained supportive of Meagan's HUG. Cindi said: "It never heals in your heart, but you keep going. Being part of Meagan's HUG is medicine for us". She also knows that if Cosimo were diagnosed today, the outcome could be quite different. "I feel thankful. The funds we have raised for research mean we have come so far. The kids now have a better chance."

Supporting pediatric brain tumour research

For 20 years Meagan's HUG has lived its mission: to raise hope and awareness about paediatric brain tumours. Supporters of Meagan's HUG have now

donated more than CAD \$5.8 million to pediatric brain tumour research.

Neurosurgeon Dr. James Rutka, Director of the Arthur and Sonia Labatt Brain Tumour Research Centre (BTRC) in Toronto has a long association with Meagan's HUG. He and his colleagues participate annually alongside his young patients in the Meagan's HUG event.

Dr Rutka said: "Meagan's Hug has filled a huge need at SickKids, and around the world, raising awareness of brain tumours in children, and providing support for state-of-the-art research to unravel the mysteries behind these tumours. Meagan's HUG funding has enabled our scientists to discover the molecular underpinnings of childhood brain tumours, and to identify novel therapeutic targets. I have been delighted by and in awe of the progress I have seen in this field through the efforts of the Meagan's HUG team."

continued ➤

One of Dr. Rutka's colleagues, Dr. Cynthia Hawkins is a Senior Scientist and Principal Investigator at the BTRC. Dr. Hawkins' lab is devoted to research into diffuse intrinsic pontine glioma (DIPG).

Dr Hawkins said: "Over 15 years we have uncovered the genetics of DIPG, helped develop an international collaborative to collect tissue and clinical data on DIPG, designed novel diagnostic tests to accurately diagnose this disease and created novel animal tissue culture models to test new potential therapies. Our lab has three articles in the top ten of all-time most cited papers on DIPG. We continue to apply the latest technologies to the study of DIPG and strive to bring our discoveries to the patient's bedside."

"This is for me, they are fighting for me"

Julian Pope was only seven years old when he was first diagnosed with a brain tumour. Too ill to walk with other Meagan's HUG participants, his mother Adrian drove him along the walking route, overwhelmed at seeing the number of people who turned out for the same cause, supporting families like theirs who were affected by a brain tumour.



Meagan's HUG Hero Cosimo Oppedisano, age ten, enjoying his time at camp

Julian recalls well the second year he witnessed Meagan's HUG which was looking down from a hospital room at SickKids where he was receiving treatment for his brain tumour and realizing "this is for me, they are fighting for me."

Julian is now 25 years old and fulfilling his childhood ambition to work in his

chosen field of architecture technology. His commitment to Meagan's HUG endures and he remains a spokesperson on behalf of youth at Meagan's HUG events and its vibrant school program, "Kids Helping Kids" which develops leadership skills in children and fosters virtues like kindness, compassion and empathy.



Dr Cynthia Hawkins (front row, fifth from left) with laboratory colleagues at the Arthur and Sonia Labatt Brain Tumour Research Centre (BTRC) in Toronto. Photo courtesy of the Hawkins lab, the Hospital for Sick Children (SickKids), Toronto, Canada, <https://www.hawkins-lab.com/people>

"Meagan's HUG is a symbol for us all and has a message for us all too," said Julian. "Meagan's HUG is like family. I watch my friends who I have met through Meagan's HUG too, and it feels good to see them become more sure of themselves, more confident."

Re-shaping pediatric brain tumour care

In 2000 world-renowned Canadian paediatric neuro-oncologist Dr. Eric Bouffet came to Toronto's SickKids to develop and lead a multi-disciplinary neuro-oncology program. That same year, he met Meagan and her family and began her treatment. A strong supporter and volunteer at Meagan's HUG, he is often a featured speaker on behalf of the organization.

Dr Bouffet urged the establishment of a fellowship to invite neuro-oncologists around the world to work for one year with him and his team. The Meagan's HUG Neuro-oncology Fellowship began in 2014 welcoming Dr. Alvaro Lassaletta, from

Madrid, Spain. Now in its eighth year, the Fellowship fosters sharing of expertise and knowledge, changing the map of pediatric brain tumour care.

"The focus on paediatric brain tumours has increased dramatically, as they are now the first cause of death from cancer in children living in high income countries, as well as an important source of morbidity among long-term survivors," said Dr. Bouffet. He also commented on the amazing progress in molecular biology and genomics that has allowed the development of new treatments. "There is not a single brain tumour meeting that goes by without a rave comment on the role of Toronto in these advances, and this would not have been possible without the tremendous support from various sources, in particular from Meagan's HUG," Dr Bouffet said.

Meagan's HUG and hope

The COVID-19 pandemic has changed the pace of the world. It has taught us the importance of staying connected

and taking care of each other. This same caring spirit is the seed that, twenty years after its foundation, remains at the heart of Meagan's HUG.

Our HUG, a symbol of hope and support, reminds us that we are not alone and that together we are stronger. Hope changes everything. ■

For more information about Meagan's HUG, please visit <https://www.meaganshug.com>. A video about the work of Meagan's HUG can be view here: <https://www.youtube.com/watch?v=oUn-cSPd5uc>

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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

Email : zbtainfo@gmail.com
<https://m.facebook.com/Zimbabwe-Brain-Tumour-Association>

Walking and cycling for brain tumour awareness in Brittany, France



Bernard Leon, founder and President of the French Association OLIGOCYTE Bretagne Ouest, writes: "On 11th October 2020 our organisation held its annual Brain Tumour Randoligo Walk (6th edition) at Locronan, a little medieval village next to Quimper in Brittany, France. We had to postpone it from April to October because of the COVID-19 pandemic.

"We were totally unaware of the echo this walk would create. To meet the authorities' requirements we had to cancel the concert we had planned and we also had to buy ready-made sandwiches and snacks in order to limit contacts to a minimum.

"In spite of all this, this walk was a tremendous success with close to 1400 people turning out - 1047 walkers and 351 mountain bikers. If you include the 55 volunteers and the children whose registrations were free, the total amount of people supporting our fight against brain tumours on



The Randoligo event in Locronan, Brittany, France, welcomed walkers and mountain bikers alike – nearly 1500 people took part.

that day rose to nearly 1500. Therefore, we had a record number of people taking part – so many ambassadors for our brain tumour awareness fight! The amount of funds raised was over € 8,500.

"The next Randoligo (seventh edition) will be in Plomelin, near Quimper, France on 10th October 2021. Please do join us!" ■

For more information on the work of Association OLIGOCYTE Bretagne Ouest and the next Randoligo event, please visit <https://oligocyte-bretagne-ouest.fr>



Some of the participants in the Randoligo event in October 2020 in Locronan, a village in Brittany, France. Bernard Leon, Founder and President of the French association for brain tumours, Oligocyte Bretagne Ouest, is on the far right.



PBTN Pediatric Brain Tumor Network JAPAN

We are working together to improve the treatments and their quality of life of the children with brain tumors in Japan.

Child Brain Stem Glioma Network

Child Brain Tumor Parents Support Group

cranio park for Craniopharyngioma patients and families

DIPG Symposium Organizing Committee

Ependymoma Parent's Community

Japan Brain Tumor Alliance

Pediatric Brain Tumor Support Group in Kinki Area "Miracle Brain"

Rainbow Colored Train

The family support group for the Pediatric Brain Tumor patients

ISPNO Family Day

ISPNO2020 Family Day has been postponed since last year, but will be held online on October 30th at 2:00 p.m. (Japan time/with simultaneous translation)

For more information about ISPNO2020 Family Day, please visit this website.

pbtnjapan.com/en/



CONNECTING BIG HEARTS & BRAINS AROUND THE WORLD

The Robert Connor Dawes (RCD) Foundation collaborates closely with organisations and researchers globally to fast-track research funding, and improve treatment options for young people with brain cancer.

We believe that more brains are better than one, and are proud to fund crucial research, clinical trials and development and care projects around the world.

Learn more at Rcdfoundation.org



SUPPORTING PEDIATRIC BRAIN CANCER MATTERS IN THE AREAS OF RESEARCH, CARE & DEVELOPMENT

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:

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SWEDISH BRAIN TUMOR ASSOCIATION



We enhance quality of life – supporting brain tumour patients and care givers through support groups, events and lectures where we share with each other and learn about the disease.

We advocate – spreading information that may be helpful to anyone who needs facts about the disease and the patient and caregiver situation.

We promote more equal care – contributing to keeping the national care programs constantly updated so that the best care and treatment methods are available to all brain tumor patients, regardless of their place of residence.

We follow the research internationally – in constant dialogue with healthcare professionals, researchers, healthcare policy and other decision makers.

For more information visit us on our website:

www.hjartumorföreningen.se

You can also find us on Facebook and Messenger:
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Survey Finds Disparities in Care of Patients with Metastatic Brain Tumors

Nicole Willmarth, PhD

Chief Mission Officer, American Brain Tumor Association

Priscilla K. Brastianos, MD

Massachusetts General Hospital Cancer Center, Harvard Medical School, USA

The development of brain metastases (BM) is one of the most feared complications of cancer due to the substantial neuro-cognitive morbidity and grim prognosis. In the past decade, targeted therapies and checkpoint inhibitors have demonstrated promising intracranial response rates for tumors of multiple histologies. As overall survival for these patients improves, there is a growing need to identify issues surrounding patient survivorship and to standardize physician practice patterns for these patients. To date, there has not been an adequate study to specifically explore these questions of survivorship and practice standardization for patients with advanced cancer and BM.

A first-of-its-kind, cross-sectional survey of patients, caregivers and physicians on the diagnosis and treatment of brain metastases, conducted by the American Brain Tumor Association (ABTA), as part of its Metastatic Brain Tumor Initiative, revealed disparities in communication as well as practice patterns around metastatic brain tumors. These data highlight the need to increase clinical trial accessibility, standardize treatment recommendations and improve physician-patient communication reflective of the unique needs of patients with brain metastases (BM). The survey results have been published open access in the journal *Neuro-Oncology Practice* (<https://doi.org/10.1093/nop/npab042>).

What the survey data told us

Survey data overwhelmingly revealed the critical need to increase accessibility and availability to clinical trials, by



Dr Nicole Willmarth

both academic and private practice physicians. More than half of physicians indicated more clinical trials are needed. Unfortunately, participation in a clinical trial was among the least recommended treatment options. In addition, the majority of academic (72%) and private practice (59%) physicians reported that one or more of their patients was denied participation in clinical trials, specifically due to the presence of BM.

"It is critical that patients with brain metastases have more clinical trial options," said one of the study's authors, Priscilla Brastianos, M.D., associate professor of medicine and director of the CNS Metastasis Center at Mass General Cancer Center. "Historically, patients with a brain metastasis have been excluded from clinical trials. Expanding eligibility across all clinical trial phases is essential to discovering effective treatments for this population."



Dr Priscilla K Brastianos

Survey data also identified disparities in recommended treatment options among private practice and academic physicians. Data suggests private practice physicians (61%) compared to academic physicians (40%) are significantly more likely to recommend whole brain radiation. Academic physicians (56%) are more likely to recommend cognitive-sparing stereotactic radiosurgery (SRS). While whole brain radiotherapy (WBRT) was the gold standard for BM for several decades, many oncologists have recently eschewed WBRT in favor of SRS for BM due to the risk of neurotoxicity and the lack of improvement in quality of life or overall survival with WBRT.

The possible rationale for the discrepancy in treatment recommendations may be an outcome of how physicians approach treatment recommendations. Survey data shows academic physicians were more likely to consider clinical

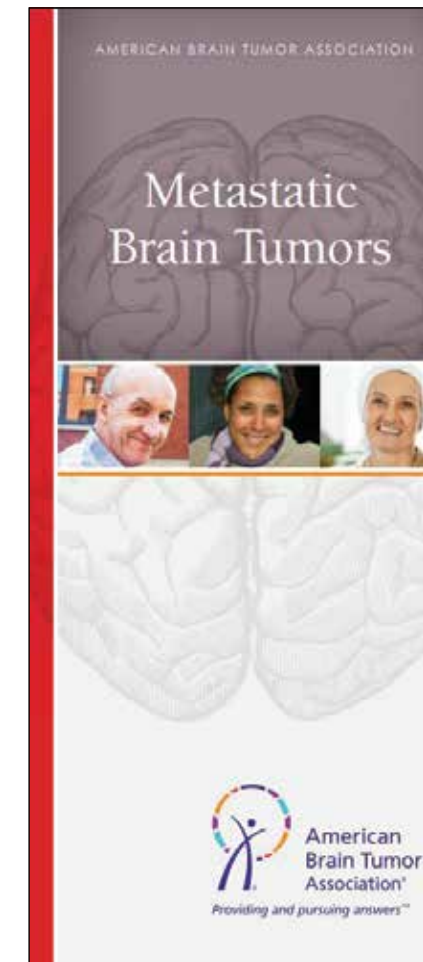
research and treatment toxicity in their decision-making process, whereas private practice physicians were more concerned about treating neurologic symptoms.

The survey also revealed a disparity in the perceived discussion of topics pertaining to BM. For example, only 48% of patients said they were informed of symptoms to be aware of but 80% of physicians responded that they discussed this topic with their patients.

"While treatment and care of patients with brain metastases presents unique challenges for the physician and patient, this survey sheds some light on interventions needed to address the complex and unique needs of this patient population," said Nicole Willmarth, PhD, chief mission officer of the American Brain Tumor Association (ABTA) and author on the study. "Through the ABTA Metastatic Brain Tumor Initiative it is our intent to collaborate with the medical oncology and brain tumor communities to better address these unmet needs and help deliver better outcomes for this patient population."

Survey Methodology

The cross-sectional online survey of patients, caregivers and physicians, conducted online by Penn, Schoen, and Berland (PSB) on behalf of the ABTA, analyzed approximately 200 responses from each cohort. The patient and caregiver survey was conducted from August 13 to September 16, 2018 and the physician survey was conducted from June 16 to 25, 2019. Surveyed patients were



The American Brain Tumor Association (ABTA) provides a range of educational material about metastatic brain tumors

adults diagnosed with brain metastases, caregivers providing support to a patient with brain metastases, and physicians providing direct clinical care to patients diagnosed with BM.

About the Metastatic Brain Tumor Initiative

Metastatic brain tumors are the most common type of brain tumors in adults. Current estimates suggest approximately 50,000 to 150,000 adults are diagnosed with brain metastases annually in the U.S. Unfortunately, the average prognosis has historically been in the order of a few months. Lung, breast, melanoma, kidney, and colon cancers are the most common primary cancers leading to brain metastases.

As leaders in brain tumor education, support services and research, the ABTA created the Metastatic Brain Tumor Initiative to inform, support and empower patients diagnosed with a metastatic brain tumor. Partner organizations include the Kidney Cancer Association, Living Beyond Breast Cancer, LUNGEVITY Foundation, Melanoma Research Foundation, and the Society for Neuro-Oncology. ■

Metastatic Brain Tumor Patient Resources

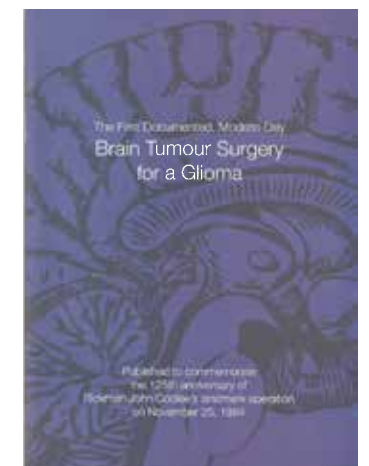
To help inform and empower patients and caregivers impacted by a metastatic brain tumor diagnosis, the ABTA provides free access to the *Metastatic Brain Tumors* educational brochure, *Metastatic Brain Tumors - Questions to Ask Your Doctor* fact sheet, and an archive of Patient and Family Meetings and educational webinars dedicated to understanding brain metastases treatment and care. ABTA resources are available via abta.org.

Dr Rickman John Godlee's landmark brain tumour surgery in 1884

In 2009, the IBTA published a booklet about *The First Documented, Modern-Day Brain Tumour Surgery for a Glioma* about the landmark operation which took place in London, UK on 25th November 1884. The IBTA booklet commemorates the 125th anniversary of this event. Performed by Dr Rickman John Godlee on a young man named

John Mitchell, the IBTA booklet contains previously unpublished material about the case.

In 2009 only a very limited number of these booklets were printed and distributed. The IBTA is now delighted to make this publication more widely available as an e-booklet which can be downloaded by visiting the IBTA website at www.theibta.org ■



Did you receive *BRAIN TUMOUR* magazine in a personally addressed wrapper?



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Celebrating a decade of community service in the healthcare sector.

Rainbows and Smiles is a childhood cancer foundation based in South Africa and this year we celebrate our 10th anniversary. Our mission is to provide, emotional, social and financial support to underprivileged families and caregivers of children diagnosed with cancer.

An average of 800 – 1000 children are newly diagnosed annually in South Africa. Rainbows and Smiles encourages childhood cancer advocacy with a special interest in brain tumours. We strive to educate people, with the goal of promoting early detection. Our principles include hope, smiles and relief.

Rainbows and Smiles promotes GOLD RIBBON AWARENESS to educate people, as knowing the early warning signs could save the life of a child with cancer.

As we celebrate our 10th year anniversary in the healthcare sector, we would like to take this opportunity to thank our family of supporters and donors. Without YOU none of this would be possible. Over the past 10 years our foundation has flourished and we have been able to deliver a mammoth amount of kindness.

Thank you for your beautiful hearts from our team:
Bonita Suckling, Nadia Lewis, Debbie Riggien, Graham Parker, Denise Towell, Gerrida Rorich, Debbie Blake, Catherine Klopper, Catherine Drysdale, Courtenay Fisher, Barbara Grobbelaar, Mandi Higgins, and Donovan Gaddin.


"Let's make today the funnest day ever"
Jed Brady Thomas-Suckling

For further information please do not hesitate to contact:

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VISION
A country where all brain tumour patients receive quality healthcare, patients and caregivers are well informed and supported.

MISSION
To promote delivery of quality healthcare for brain tumour patients. We also aim to provide information, support and to advocate for brain tumour patients and their caregivers in Kenya.

PILLARS

- ① To promote quality, accessible, and affordable healthcare for brain tumour patients.
- ② To engage in advocacy, creation of awareness and dissemination of information on brain tumours.
- ③ To support Research, education and innovation in management of brain tumours.

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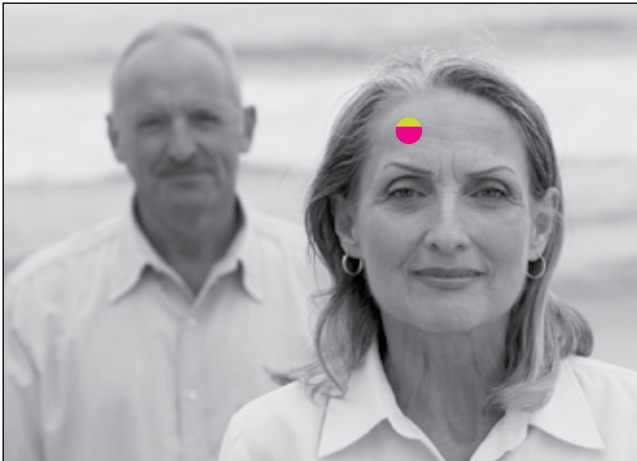
YOU NEED TO BE BRAINY TO FIGHT BRAIN TUMORS

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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.

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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.

LEARN MORE AT abta.org





BRAIN TUMOUR SOCIETY (SINGAPORE)

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
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The Danish Association for brain tumor patients and relatives

We seek to

- provide patients and their relatives with a supportive network and information
- share valuable experience between healthcare workers and patients
- increase public awareness of this patient group.

If you would like to join or support us, please contact:
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The COSMIC Project - Defining the minimum outcomes to be reported in future meningioma clinical trials

Christopher P Millward, MRCS, MBBS, MSc, BSc, Clinical Research Fellow
Institute of Systems, Molecular, & Integrative Biology, University of Liverpool;
Specialty Registrar in Neurosurgery, The Walton Centre, Liverpool, UK



The COSMIC project ('Core Outcome Sets' for Meningioma in Clinical Studies) is an international clinical research study that will shape the design of future meningioma clinical trials. The project requires healthcare professionals, researchers, patients, and those who act in a patient support capacity (such as family members, patient advocates and charity workers) to participate, in order for it to succeed. Unlike a clinical trial, this project does not test a new treatment, and offers no benefit to patients in the short-term. It is research about research, to make meningioma clinical research better! And I would like to explain why it is important that meningioma patients and those in a support capacity (as well as healthcare professionals and researchers) take part.

What is a meningioma?

A meningioma is a type of brain tumour that grows from the lining of the brain. It is the most common type of primary brain tumour. Meningiomas can cause symptoms including headache, weakness of the limbs, and seizures. Some meningiomas are found incidentally and may never cause symptoms. Some patients require surgery to remove their tumour, but it is not always possible to remove all of it. Sometimes the tumour will



Mr Christopher P Millward, Principal Investigator for the international, multistakeholder COSMIC project

grow back after removal, and further surgery, or radiotherapy may be required. There are no medical therapies effective against meningioma growth.

What is a clinical trial?

Clinical trials are conducted to provide answers to clinical problems and aim to provide evidence of the benefit (or lack of benefit) of potential new treatments. A well conducted clinical trial may be the highlight of a researcher's career because it may improve the health prospects for the next generation of patients. Unfortunately, not all clinical trials produce clear and meaningful results. It is increasingly recognised that without patient involvement in the design of clinical trials, the study may

not evaluate what really matters to patients. And it should go without saying, that clinical trials are conducted for the benefit of the patient.

How do researchers use clinical trials to answer clinical questions?

Typically, the purpose of a clinical trial is to investigate how effective a new treatment is for a particular condition. This allows decisions to be made about who should receive this new treatment, when they should receive it, and what the benefit may be. Examples of new treatments include; a novel surgical technique to remove more brain tumour tissue; the use of radiotherapy after surgery to prevent tumour recurrence; or the administration of a drug to prevent seizures in patients with brain tumours.

To evaluate how effective a new treatment is, researchers need to choose what specific outcomes to measure within a clinical trial. Broadly speaking, outcomes measure treatment benefit, for instance, the 'time to tumour recurrence'. But outcomes could also measure treatment harms, such as 'fatigue'. A method of measuring each outcome must also be chosen by researchers. Taking the example of 'fatigue' for instance, we could choose to ask the patient 'how often do you feel tired' in a questionnaire.

In a clinical trial, outcomes must be measured and reported for those who receive the new treatment, and those who do not, in order to allow conclusions to be drawn about the effect of the new treatment. If the outcomes that are measured are of no relevance to patients who would use the treatment, there is a real risk that recommendations about new treatments and their benefits, may not be of relevance to patients either.

What is the problem with meningioma clinical trials?

There have been very few clinical trials investigating new treatments for meningioma. But when the completed and published clinical trials are compared, it is clear that the outcomes that are reported in those trials are very different. This makes it difficult to compare the results of similar trials and slows the progress of medical research. For instance, if you wish to compare two anti-seizure drugs used in patients with meningioma, you would look at the effect of the anti-seizure medication (treatment) on seizures (outcome). If the outcome is measured in a different way in the two trials, for instance time to first seizure vs number of seizures per month, you cannot easily decide which drug is better.

What is the purpose of 'The COSMIC Project'?

The aim of this project is to decide which outcomes should be measured, as a minimum, in all future meningioma clinical trials. This set of outcomes is called a 'Core Outcome Set'. This would ensure that the results of future meningioma clinical trials are comparable to one another, and allow useful conclusions to be drawn from their results. Researchers are not limited to only measuring the 'Core Outcome Set'; they can in fact choose any outcomes to measure. But the 'Core Outcome Set' should be measured as a minimum.

What does participation in 'The COSMIC Project' involve?

Stage 1 - An online survey will be sent to healthcare professionals such as doctors and nurses, researchers conducting meningioma clinical trials, patients with a meningioma, and their support network. The survey will be completed twice. The first time the survey is completed, participants will see a list of outcomes and be asked to rate how important it is that each outcome is included in the 'Core Outcome Set'. Once this has been done by all participants, the process will be repeated, but each participant is given the chance to change their rating, after seeing the responses of other participant groups.

Stage 2 - Some outcomes will be neither included nor dropped following stage 1 because consensus will not have been achieved. For instance, patients may feel that 'fatigue' is a very important outcome to be included in the 'Core Outcome Set', but healthcare professionals may rate this as only moderately important. A meeting will take place with a range of participants, including patients, and undecided outcomes will be discussed until consensus is reached. At the end of this meeting, there will be agreement on which outcomes should be included in the meningioma 'Core Outcome Set'.

Who is collaborating with 'The COSMIC Project' and how can individuals participate?

There is little point in developing a core set of outcomes if researchers do not use it when designing a new meningioma clinical trial. We have collaborated with worldwide organisations and individuals who are leaders in meningioma clinical research. By doing this, we hope that our efforts to improve meningioma clinical trials becomes a reality.

We have obtained support not only from the International Brain Tumour Alliance (IBTA), but from the following organisations; the European Organisation for Research and Treatment of Cancer Brain Tumour Group (EORTC BTG), the International Consortium on Meningioma (ICOM), the European Association of Neuro-Oncology (EANO), Society for Neuro-Oncology (SNO), Response Assessment in Neuro-Oncology Patient-Reported Outcome Group (RANO-PRO), British Neuro-Oncology Society (BNOS), Society of British Neurological Surgeons (SBNS), British-Irish Meningioma Society (BIMS), The Brain Tumour Charity (TBTC), Braintrust – the brain cancer people, and the Brain Tumour Foundation of Canada. ■

Further information is available on The COSMIC project study website at www.thecosmicproject.org. Registration and the first round of the eDelphi survey will open to participants later this year, and email invitations will be sent through mailing lists. We hope a large number of meningioma patients and those in a support capacity will take part so that future meningioma clinical trials measure what really matters to them.

What's new?

To receive your free copy of *Brain Tumour* magazine, please visit: <https://theibta.org/our-publications/#e-News>

The IBTA also publishes a monthly e-News containing information of interest to our international brain tumour community such as treatment advances, cutting edge research, patient organisation news, industry news relevant to brain tumours and a listing of forthcoming conferences and meetings.

Please visit: <https://theibta.org/our-publications/#e-News> to subscribe.



PVW Brain Tumor Foundation

We ...

- raise awareness of brain tumors in the community, and
- provide support to those affected by brain tumors

Set up in Hong Kong in honor of bass trombonist Pieter Vance Wyckoff, we encourage everyone to *Play Your Part!*



www.pvwbraintumorfoundation.org.hk



Objectives:

- To bring together Brain Tumor Community
- To provide information, guidance, counselling
- Psycho-social support for patients and care givers
- Self-help groups for patients and care givers

Discussions on Various Topics:

- Occupation - options
- Vocational Training
- Education support for siblings/ children of Brain Tumor affected.
- Psychological support and counselling
- Social Integration
- Financial security
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We Can Help You By:

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- Setting up Peer Support Group at your Centre
- Training Psychologists and Counsellors

Who can associate with us?

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Clinicians - Neurosurgeons, Radiation and Medical Oncologists
Hospitals
Various adult and paediatric cancer patient support groups

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SECTION 8 NOT FOR PROFIT ORGANISATION

In the UK
brain tumours
kill more children
and adults under
the age of 40
than any other
cancer

Just
1%
of the national spend
on cancer research
has been allocated to
this devastating
disease

**Brain Tumour Research
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Together we will find a cure

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NZBT is a charitable trust which recognises the need for patient and research support in New Zealand, and aims to make a real and positive difference to the lives of people of all ages diagnosed with a brain tumour.

The Trust seeks to promote a culture of healing, wellbeing, and support at all stages of an individuals' experience with a brain tumour, both cancerous and benign, also supporting their family and whānau.

The Trust also aims to help brain tumour patients by underwriting research, providing funding, and encouraging the newest therapies to New Zealand through clinical trials.

Through Ihi a Rangi New Zealand Brain Tumour Trust, we seek to bring the promise of better therapies, care, and cure.

[@nzbraintumourtrust](https://www.facebook.com/nzbraintumourtrust)

www.nzbt.org.nz




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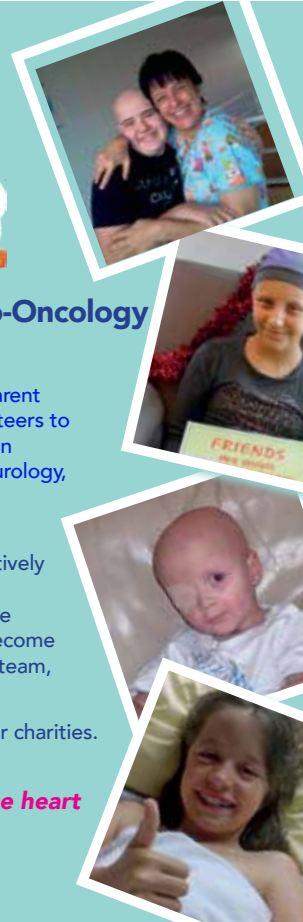
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ISNOCON - Report of the 12th Annual Conference of the Indian Society of Neuro-Oncology

Ranjith K Moorthy, Professor

Neurosurgery II, Department of Neurological Sciences, Christian Medical College, Vellore, India



The 12th annual meeting of The Indian Society of Neuro-Oncology (ISNO) was hosted as a virtual event by Christian Medical College, Vellore in South India from April 15-17, 2021. This was the first virtual conference of the Society, being held in the midst of the COVID-19 pandemic.

Despite the meeting being held through a virtual platform, there were more than 300 registrants from India, the United Kingdom and Asia and the sessions were well attended with active participation from the delegates who were from the disciplines of neurosurgery, neuropathology, neuroradiology, radiation and medical oncology (adult and paediatric) and basic neuroscience. Information booklets on brain tumours translated into the Indian languages of Assamese and Tamil by JASCAP (Jeet Association for Support To Cancer Patients) were released during the inaugural function. The mission of JASCAP is to "Empower families through relevant and updated information on cancer and its management".

ISNOCON Day 1

On the first day of the meeting, the focus was on management of primary spinal tumours and metastatic spinal tumours. The faculty included luminaries in the field of management of sarcomas, chordomas and spinal metastases such as Dr. Silvia



Professor of Neurosurgery Dr Ranjith K Moorthy and Organizing Secretary of ISNOCON 2021

Stacchiotti from Milan, Italy; Dr. Arjun Sahgal and Dr. Michael Fehlings from Toronto, Canada among others. The talks and discussions focussed on contemporary

practices in the management of these tumours. The highlight of the day was the presidential oration delivered by Dr. Shaleen Kumar, radiation oncologist and director of Superspecialty Cancer Institute and Hospital, Lucknow in Northern India. In his oration, Dr Kumar gave insights into the processes and challenges involved in starting an oncology centre under the public sector.

ISNOCON Day 2

The second day of the meeting was devoted to intramedullary spinal cord tumours, gliomas and translational research in neuro-oncology. Dr. David Capper from Berlin delivered a keynote address on the use of DNA methylation in classification of brain tumours. Dr. Yong Kil Hong, president of the World Federation of Neuro-Oncology Societies summarized his experience of Tumour Treating Fields



A view of the ISNOCON 2021 virtual meeting platform with ongoing discussion on vertebral tumours in progress



A screenshot showing the introduction of Dr. Mark R Gilbert (top left panel), Senior Investigator and Chief of the Neuro-Oncology Branch in the Center for Cancer Research, National Cancer Institute (NCI), at the National Institutes of Health (NIH) in Bethesda, Maryland, US, during his Abhijit Guha Oration. Also pictured are Dr. Shaleen Kumar, president of ISNO, (middle, left panel) and Dr. Rakesh Jalali (bottom left panel)

in glioblastoma. In the "Do Not Miss It" session, a preview was presented on what to expect once the revised *Classification of Tumors of the Central Nervous System* is released by the World Health Organization (WHO) later this year. Dr. Arie Perry from the University of California San Francisco (UCSF), USA; Dr. Chitra Sarkar from AIIMS, Delhi; and Dr. Cynthia Hawkins from The Hospital For Sick Children, Toronto, Canada presented a synopsis of the classification and the rationale. Dr. Vani Santosh from NIMHANS, Bangalore provided insights into how the WHO 2021 recommendations would affect reporting and diagnosis of gliomas in India and other low and middle income countries. This was followed by an enthusiastic discussion on the WHO 2021 recommendations and it was planned to formulate pragmatic guidelines on its application and use in the Indian scenario.

The ISNO President's Award for Best Clinician-Researcher was awarded to Dr. Jayant Goda Sastri, a radiation oncologist from Tata Memorial Hospital, Mumbai for his work on preclinical drug development on glioblastoma. The ISNO President's Award for Outstanding Work in Neuro-Oncology was given to Dr. Kirti Gupta, a

neuropathologist from PGIMER, Chandigarh for her contribution in understanding molecular pathology of paediatric posterior fossa tumours.

The Abhijit Guha Oration, in memory of the late Dr. Guha from Toronto, who spearheaded the establishment of ISNO, was delivered by Dr. Mark S Gilbert, Chief of the Neuro-Oncology Branch in the Center for Cancer Research, National Cancer Institute (NCI), at the National Institutes of Health (NIH) in Bethesda, Maryland, US. Dr. Gilbert presented his work on the classification of ependymomas and gave insights into various aspects of research that advanced care of patients with CNS tumours. He conveyed the message to the audience, particularly relevant to young investigators, that one should be willing to keep all doors open and welcome any iota of chance and opportunity that may come knocking.

ISNOCON Day 3

The third and final day of the meeting was focused on the management of CNS tumours in teenagers and adolescents or the AYA (adolescent and young adult) population. This session was introduced by Dr. Prakash Chitalkar, medical oncologist

from Indore, who is the president of the TYAcn Foundation. The keynote address was delivered by Dr. Anita Mahajan, a radiation oncologist from Toronto, on the challenges of administering radiation therapy to this population. Dr. Rakesh Jalali summarized the Indian experience of the management of these tumours.

Enthusiastic participation and vibrant discussions from delegates

There were three theme-based challenging case discussions held on each of the three days of the conference with a multidisciplinary panel of experts. There was enthusiastic participation from both the delegates and faculty to discuss various aspects of diagnosis and management in each of the cases.

The conference ended on a high note with a very exciting quiz competition amongst six finalists, who were residents from different institutions across India.

Despite the virtual nature of the meeting, there were vibrant discussions on matters related to neuro-oncology and its practice in centers in India, some of which may lack the infrastructure available in Europe and North America. ■



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Fondazione Heal through fundraising, events and solidarity campaigns, funds scholarships and scientific research projects for the study and treatment of childhood tumors of the central nervous system.

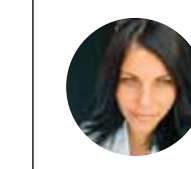


ILAM
The Israeli Brain Cancer Association


ILAM has published a digital booklet on rights for patients in Israel with glioblastoma (GBM), including recent changes for improved benefits for GBM patients and their families

For more information:
www.ilam.org.il

Dr. Keren Gonen, CEO of the Association:
"I am proud to advance changes for the benefit of patients and I am grateful for the cooperation with the National Insurance Institute of Israel for the willingness to take action to better the quality of life for patients in general and GBM patients in particular."



Dr. Keren Gonen, CEO of ILAM



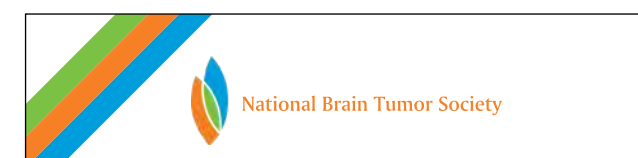
Meir Shpigler, NII Director General



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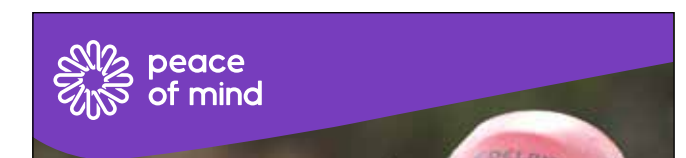
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Medication use for patients with cancer – how can patients and pharmacists work together and work better?



Dr Mirjam Crul, Hospital Pharmacist

and Maurien Rombouts, Hospital Pharmacy Resident

Amsterdam University Medical Center, Division of Pharmacology and Pharmacy, The Netherlands

The diagnosis of cancer is most often followed by a wide range of newly-prescribed drugs. At some point in the treatment, anti-cancer drugs will most likely be prescribed. Some anti-cancer drugs are administered in the hospital or in a day-care unit, but more and more anti-cancer drugs that can be taken orally, have recently reached the market. This means that the patient, or his or her caregivers, are in charge of taking or administering these drugs appropriately at home. In addition, drugs to alleviate symptoms of the disease, or drugs to alleviate symptoms of the treatment, are prescribed to the vast majority of patients with cancer. More often than not, this will lead to very complex regimens of a whole array of different pills, capsules and even syringes.

Pharmacists who have specialized in oncology care, can be of service to patients to support them in optimizing their drug regimens. In this article, we aim to give you an overview of the attempts of the pharmacy department of Amsterdam University Medical Center in The Netherlands to work together with patients to improve their pharmaceutical care during treatment for cancer.

Medication reconciliation

Some patients receive the diagnosis of cancer without having any previously existing disease. Since the incidence of cancer increases with age though, we mainly see patients, who are diagnosed with cancer, already taking multiple medications for diseases such as hypertension, diabetes or rheumatoid



Pharmacists Mirjam Crul (left) and Maurien Rombouts (right) offer “medication reconciliation consults” to cancer patients, including brain tumour patients, at Amsterdam University Medical Center

arthritis. It is very important for the medical team treating the patient with anti-cancer treatment, that they are aware of these other diseases and how they are treated. Therefore, in our hospital we started several years ago with what we call “medication

reconciliation consults” for all patients who are admitted to our hospital. Medication reconciliation means that we discuss the actual medication use for each patient with the patient, before we enter any prescriptions into the hospital electronic

patient records. We find it important not to just look into the computer system and see what drugs have been prescribed by doctors (including general practitioners) but to learn how they are used in a patient’s daily life by asking the patient in person.

These consults are incredibly helpful for the rest of the treatment, in several ways:

1) If a patient has experienced negative outcomes from a drug, we can note this in the records, and thereby include a warning sign, that will automatically appear when a new doctor starts prescribing a new drug that is very similar, for example from the same class. Of course, sometimes it may not be possible to avoid starting that drug, but in this way a better estimate of the benefits versus the risks can be made by the patient, doctor and pharmacist.

2) Some drugs can reduce or enhance the effects of other drugs. We call that drug-drug interactions. By having an actual medication list for each patient, we can predict such possible interactions with the new treatments that are foreseen. And if necessary, we can adjust the treatment accordingly.

3) Many automatically generated medication lists are based on dispensing records from community pharmacies. Although helpful, these are often not a proper reflection of what a patient is actually taking.

Some examples might be:

A pharmacy will dispense a drug for hypertension at a dose of 100 mg, in a package of 50 pills. The patient starts taking these, goes back to the GP and finds out that their blood pressure is so adequately controlled that the GP advises that a 50 mg dose is actually enough. After this, the patient will take half tablets, but this will only become visible in the pharmacy dispensing log, when the package of 100 mg pills is used up. If the patient is admitted in the meantime to the hospital, and the records are just copied, there is a risk that 100 mg will be prescribed by the hospital doctor. Of course, this should be avoided.

Also, when a patient stops taking medication because of side effects right after the start of a new drug, the pharmacy records do not always show this. You do not want to give the patient the same drug again when he/she is admitted to the

hospital. Sometimes a patient is getting drugs somewhere other than his or her own pharmacy, which is also not shown in the records. Therefore, we are convinced that the patient, or his or her caregiver, should always be asked about the most recent medication use.

During hospital stays, we also see a lot of changes in a patient’s medication. Again, this can result in rather complex drug regimens that are distinctively different than the regimen pre-admission. For this reason, one of the pharmacy staff members will also visit each patient shortly before discharge, to talk through the medication list, and to explain which drugs have been altered (which could mean a dose change, but also starting or stopping a drug) and to give advice on how to best take the drugs. The community pharmacy is then sent an updated list - if the patient gives permission for this - so that the community pharmacy can update its own records of the patient’s medication use.

Medication dispensing

For each new drug that is dispensed to a patient, explanations on its use and possible side-effects are given to the patient both verbally and in leaflet form. We call this a “first-dispensing consult”. When a patient visits us again, we ask how he or she is doing, if the medication meets the needs of the patient and if any unwanted effects have become apparent. If they have, we try to find the best advice on how to manage such unwanted effects. This is what we call a “second-dispensing consult”.

The content of these consults is something that we try to improve and individualize, because each patient is unique. We are very grateful that our pharmacy is in contact with patient societies such as the International Brain Tumour Alliance, and we find the advice that we receive from them beneficial in optimizing our patient consults.

Complementary and Alternative medicines

A diagnosis of cancer is overwhelming for everyone.

One of the difficult issues to cope with is the feeling that one is unable to take control of events unfolding. In general,

most treatment decisions are made by a team of medical specialists, and there is often not much choice for the patient. In the meantime, the patient will experience negative effects of the disease and/or of the treatment. In this case, many patients will try to alleviate their symptoms or treat their disease by taking additional measures.

Anything that is not in the standard of care, is referred to as “complementary and alternative medicine” often abbreviated CAM. CAM ranges from body-mind interventions or energy therapies to taking biologically based therapies such as specific food supplements, herbal treatments, dietary alterations or traditional non-western medicines. Many pharmacists are gaining more knowledge on these complementary and alternative medications, as more data on them become available.

As yet, the beneficial effects of such treatments are not often researched in the way traditional Western medicines are. Therefore, giving adequate advice on whether to use them and if so, how to use them, is not always possible. However, in some cases, we do know if interactions between the alternative medication and the regular treatments will occur. We have experienced that sometimes, patients are reluctant to share information about their use of CAM with their hospital treatment team. Maybe, they fear being judged for it. This is something that we want to overcome in our hospital. We feel that it is always best to create an atmosphere where any patient can share his own ideas and beliefs. That is also why we talk about the use of alternative medicine in medication reconciliation. If we have knowledge about what kind of CAM someone is using, we can then do a check to see if there is a potential for interactions with for example, chemotherapy. If we then share the results of this check with the patient in terms of a risk-benefit assessment, this will allow the patient to make an informed decision with the most information that is available.

Advice during treatment

Cancer is not a static disease.

Often, medicine regimens will be adapted during treatment, based on effectiveness or toxicity. In any stage of the disease and treatment, patients can

continued ►

have questions and concerns regarding their medicines. To also be able to help patients in between in-hospital consults we have very recently set up an electronic option in the patient portal of their electronic records, where a question to the pharmacy team can be written down. We see those questions coming in every day and answer them on the same day. This process goes through an encrypted route that ascertains privacy.

Sometimes, we need more information, and then we ask the patient if we may

call him or her to discuss the issue. This is new for us, so we are learning along the way, and are also still thinking about how to make such a question section accessible for patients who prefer non-digital communication.

Conclusions

Nearly all of the patients who are diagnosed with cancer will need to take medicines at some stage of their treatment path. The range of drugs that are used is increasing quite rapidly, and so is our knowledge and

understanding of their interactions. We try to optimize our pharmaceutical services to better cater to patients' needs. And we are grateful for the support and advice that the International Brain Tumour Alliance and other patient organizations are offering us.

We realize that the services between countries and even between regions within countries are still variable. Therefore, we also try to disseminate our center's experience to colleagues and patient advocacy groups.

Together, we can improve optimal medication use. ■

A dynamic worldwide community



The International Brain Tumour Alliance (IBTA) brings together experience and expertise from all over the world with the aim of enhancing the well-being and quality of life of brain tumour patients and their families.

We work across the globe with Alliance supporters, researchers, medical professionals, pharmaceutical and device companies, academia, government agencies, medical societies, key opinion leaders and others involved in the field of neuro-oncology.

We place patients, their families, and caregivers at the heart of all we do, celebrating their courage and achievements, sharing knowledge and experiences, and working together for progress.

We proudly collaborate with established brain tumour patient charities and not-for-profits; we also encourage the establishment of such organisations in countries where they don't yet exist.

We identify collaborative actions across our international community and work towards our vision of a world free from the fear of brain tumours. ■

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- **Abstract Submission Due Date**
- September 27 (Mon), 2021
- **Abstract Acceptance Notice**
- Mid November 2021
- **Early Bird Registration Due Date**
- January 12 (Wed), 2022

It's time to find a cure for brain cancer!

Charles La Haye, Founder and Chairman
Stichting Sterk en Positief, The Netherlands



During my first rounds of chemotherapy in early 2019, my wife Natascha and I established the foundation **Sterk en Positief** (Strong and Positive).

My name is Charles La Haye and I have an astrocytoma. I was operated on in the beginning of 2018 and I was lucky to receive proton therapy at Holland PTC (proton therapy centre) in Delft, the Netherlands. Twenty-eight radiation sessions followed a year of chemotherapy and I received the drug temozolomide that was developed decades ago.

We had several reasons to establish Sterk en Positief.

First of all, we wanted to do something to give back for the neurosurgeons, neuro-oncologists, and nursing staff. Why? Simple! We were wondering how life must be for them. Telling brain tumor patients bad news on a daily basis. This must be so frustrating! Another reason was that I could not understand why research was not progressing. And the last reason? I want to leave something behind when I am gone.

So we started our mission to raise money for research. Dr. M.L.D. Broekman, MD PhD LLM, neurosurgeon at the HMC Hospital in the Hague gave us a goal to collect €280,000 for research into bypassing the blood-brain barrier with local therapies.

We have worked hard, and over the



Charles La Haye

last two years we have developed into a professional, dedicated and caring foundation with the focus on raising money and collecting all news about brain tumor research in one place.

Collecting this research news from all over the world is a fantastic job. Our followers know that our foundation is a place to find relevant information and that it is carefully explained, for everyone to understand.

The benefit of this work is that we learn a lot about this incredible world of DNA, lab work and new techniques in the world of brain tumors.

I strongly believe in focused ultrasound; that this technique will allow for opening of the blood-brain barrier, which could result - when given in combination with potent drugs - in killing the tumor.

We are very happy that, in January this year, UMC Utrecht and the Princess Maxima Center in Utrecht, the Netherlands, invested in an MR-guided focused ultrasound (MRgHIFU) system.

We are even more pleased that recently, together with the Dutch Brain Foundation (Hersenstichting), we received €1.6 million to start a project to find a solution for brain tumors using this new technique.

Listening to experts, they say that the key to overcome brain tumors is the combination of focused ultrasound and immunotherapy. Let's hope they are right.

Over the last six months funding for research here in the Netherlands has really been increasing, and more funding has been generated for brain tumor research:

■ €3.9 million for targeting brain tumors with a laser at Radboud University Medical Center.

■ €800,000 for the project GLOW (personalised medicine) in Utrecht Medical Center/ Haaglanden Medical Center.

There is also an interesting project at Erasmus MC Rotterdam focusing on oligodendrogliomas and the enzyme D2HGDH. This project is made possible by Peter Robert, also a patient who, just like us, wants to find a cure. For more information on this research, please visit www.sterkenpositief.nl/onderzoek.

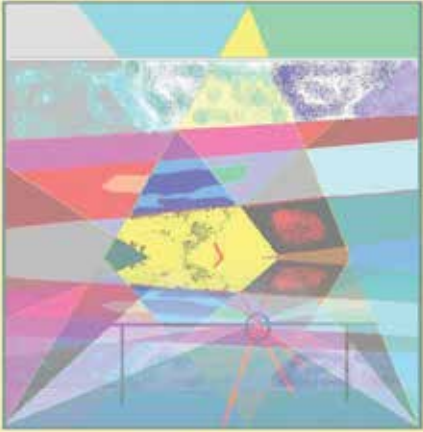
Reading about all of this research news, I really believe, now is the time to find a cure for brain cancer!

As a brain tumor patient, I want to state this: **please share your information with other researchers all over the world. Because for us, it is an urgent matter of surviving.**

Please work together and find a cure for this devastating cancer. ■

For more information about the work of Sterk en Positief, please visit www.sterkenpositief.nl

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OUR OBJECTIVES -In the era of genomic medicine-
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.
Create a society more adapted to rare cancer patients and their caregivers and provide them with relevant information and a higher quality of life.

OUR NETWORK IN JAPAN
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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
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Norwegian Cancer Society and Norwegian Brain Tumor Association donate NOK 17 million to establish new expert group for brain tumours

Professor Rolf Bjerkvig to lead this major new investment in brain cancer

The Norwegian Cancer Society has donated NOK 15 million for the establishment of a new expert group for brain tumors. The Norwegian Brain Tumor Association has also donated NOK 2 million to the expert group. In a few years it is hoped that the Norwegian Brain Cancer Center, will be a center of expertise.

The new center will see leading Norwegian researchers and clinicians collaborating to share research data and expertise as well as collaborating on clinical studies. International cooperation will be strengthened and new and experimental treatments will be offered to patients.

The money for the establishment of the expert group comes from the fundraising campaign "Krafttak mot kreft", loosely translated to mean "valiant effort against cancer", which in the last two years has focussed on poor prognosis cancers.

Initiatives give hope to brain cancer patients

Brain cancer is one of these low survival cancers. Every year, 200-250 people in Norway are affected by glioblastoma, the most aggressive brain tumor. Less than five percent of patients survive, a dismal survival statistic which has stood almost still for 40 years.

The Norwegian Cancer Society has previously established expert groups for lung cancer and pancreatic cancer. The goal of the expert groups is to increase both survival and quality of life for those affected by these cancers. These are long-term initiatives that give hope to patients and patient groups who have seen little progress over many years.



Professor Rolf Bjerkvig, University of Bergen, Norway. Photo: Nicki Twang, copyright: Kreftforeningen

Dr Rolf Bjerkvig, professor at the Department of Biomedicine at the University of Bergen will lead the initiative. Dr Bjerkvig has been researching brain tumors for over 30 years, and in 2015 received the prestigious King Olav V's cancer research award.

In Norway, research into brain tumors has been fragmented, and there has been surprisingly little collaboration. It is hoped that the creation of this expert group will lead to more cooperation and less competition and that collaborative

work will give better results in research, clinical activities, and treatment. This, in turn, is a trigger for increased international cooperation. For example, new technology developed in South Korea and Luxembourg is one of the first things the Norwegian Brain Cancer Center will put in place. The technology focuses on creating micro-tumors from human tumor tissue removed during surgery against which doctors can test hundreds of different cancer drugs to find the right treatment for the individual patient.



Nina Jensen (right), Nicolai Roan (left) and their son Eik (photo from the private collection of Nina and Nicolai)

Nina and Nicolai's journey – an important legacy helping others

Nina Jensen, a member of the board of the Norwegian Brain Tumor Association, environmental activist and leader of the research and expedition ship REV Ocean has also become an important voice in the Norwegian brain tumor community. After her partner, Nicolai Roan died of glioblastoma in July 2019 at age 38, Nina became very involved in the brain cancer arena. She has spoken of her and Nicolai's story in the media, worked hard to raise funds during "Krafttak mot kreft", become a board member of the Brain Tumor Association and, among other things, worked to help create the new expert group on brain tumors.

Nina said: "News of the establishment of the Norwegian expert group on brain tumors has greatly encouraged me and I literally cried with joy when I heard about

the funding award. One of Nicolai's most important wishes was to help others who suffer from brain cancer. So being able to fulfil that desire is one of the greatest things I can help achieve in Nicolai's memory and in memory of others who have died from this horrible disease. And the funding award gives me hope that others do not have to end up in the same situation as us."

Secretary General of the Norwegian Cancer Society Ingrid Stenstadvold Ross said: "Nina deserves a big thank you. Her openness and commitment mean an enormous amount, both for individuals and for the cancer cause. Many thanks also to everyone who gave money during "Krafttak mot kreft". It pays to contribute! The foundation is now being laid in Norway for a solid, competent environment in brain cancer." ■

This article is based on a press release from the Norwegian Cancer Society, www.kreftforeningen.no

The new Norwegian expert group on brain tumors will:

- gather leading clinicians and researchers from different parts of the country into one, interdisciplinary environment
- establish a national patient brain tumor register and biobank and facilitate existing clinical studies
- offer Norwegian brain tumor patients access to new and experimental treatments, mainly through new technology for personalized treatment
- strengthen international research collaboration

The Norwegian Cancer Society's expert group for brain tumors includes:

- Tor Ingebrigtsen, Professor - University Hospital of Northern Norway / University of Tromsø
- Ole Solheim, Chief Physician - St. Olavs Hospital / NTNU
- Rolf Bjerkvig, Professor (Group Leader); Terje Sundstrøm, Chief Physician; Tor-Christian A. Johannessen, Chief Physician; Hrvoje Miletic, Chief Physician / Professor - Haukeland University Hospital / University of Bergen
- Einar Vik Mo, Chief Physician; Petter Brandal, Chief Physician; Iver A. Langmoen, Professor - Oslo University Hospital / University of Oslo
- Tom Børge Johannessen (Deputy Chairman), The Norwegian Cancer Registry

IBTA and the European Cancer Organisation: working in partnership for high-level EU cancer policy

Richard Price, Head of Policy
European Cancer Organisation (E.C.O.)



Europe's Beating Cancer Plan, published by the European Commission in February of this year, boldly commits to marking "the beginning of a new era in cancer prevention and care, where patients have access to high-quality screening, treatments and the latest state of the art technologies, with support at EU level that allows scale and specialisation, while fully respecting Member States' responsibilities in health policy."

Seasoned health policy advocates in Brussels (myself among them at times) are still rubbing their eyes with some element of disbelief, at the energy and pace of action by the European Commission in the short period that has followed the Plan's publications. Pledges made on paper are now quite quickly (by usual Brussels standards) being turned into practical initiatives. The most recent evidence of this has been the publication of over 40 different financed calls under the new €5.3 billion EU4Health programme, many of which directly support the ambitions of the EU's landmark Beating Cancer Plan.

So what can all these fresh names, acronyms and projects mean in real and practical terms for brain tumour patients in Europe? There are so many that might be picked out of the 42 headline initiatives



Richard Price of the European Cancer Organisation

of Europe's Beating Cancer Plan. I have chosen to highlight three that presently occupy the attention of the European Cancer Organisation (E.C.O.) in particular, and for which we are so pleased to be benefitting from the advice and guidance of the International Brain Tumour Alliance (IBTA) in our representation activity.

A new EU Network of National Comprehensive Cancer Centres in every EU Member State

What are the best available means for the EU to help support more equitable access of cancer patients to high quality care, no matter which country they are in? A key tool envisaged by the European Commission is to grow the availability of Comprehensive Cancer Centres that connect with each other, operate to agreed standards and distribute better access to high quality diagnosis and treatment. So a core 'flagship' proposal

of Europe's Beating Cancer Plan is to create a new EU Network of National Comprehensive Cancer Centres by 2025. Amongst the clear stated purposes include improving patient access to the latest innovative treatments and improving patient mobility to ensure patients with complex conditions can receive more optimal treatment than presently the case. Indeed, Europe's Beating Cancer Plan aims to ensure that 90% of eligible patients have access to such centres by 2030.

Very soon after this announcement many stakeholders quickly saw the great potential for this initiative to upgrade the pan European cancer research infrastructure for clinical, translational and outcomes research through the enhanced interconnection of Comprehensive Cancer Centres. The "Porto Declaration" of May 2021, signed by the European Cancer Organisation, applauds the expressed EU ambitions on comprehensive cancer care, and urges early action to ensure the ten EU countries presently without such accredited centres be assisted in creating this model of treatment at the earliest possibility.

The European Cancer Organisation's Quality Cancer Care Network, supported by the participation of the International Brain Tumour Alliance, is presently concluding the agreement of a stakeholder consensus position on how to ensure the maximum utility of this element of the EU's Beating Cancer Plan. Formed well, with an assurance on standards and quality, it is conceived that the new EU Network of National Comprehensive Cancer Centres could support the tangible achievement of such goals as: by 2030,

achieving a ten-year cancer-specific survival for 75% of patients diagnosed; and a doubling of survival for poor prognosis tumours.

A European Health Data Space to support improved care, research and policy making

The European Commission's proposal to create a European Health Data Space aims to provide a common framework across EU Member States for the sharing and exchange of quality health data such as electronic health records, patient registries, and genomic data, in order to support healthcare delivery, but also to facilitate health research, policymaking, and legislation.

The Health Data Space proposal comes in response to something the combined cancer community, and health stakeholders more generally, have been raising for some years: the opportunities available from the vast amount of data produced in healthcare across Europe are not yet being achieved, with unresolved structural and systemic barriers among the reasons. We remain 'data-rich and information poor'.

As members of the European Cancer Organisation's Patient Advisory Committee, the International Brain Tumour Alliance is helping to shape the cancer community's response to this opportunity. With the support of IBTA, we are advocating, among other points, that close connection be formed with the development of the European Health Data Space and the results and progress already being gained by ground-breaking collaborations between cancer centres facilitated by the European Reference Network (ERN) for Rare Adult Solid Tumours (EURACAN). It's vital that we get these new initiatives right in order to yield the strongest benefit for all cancer types, including brain tumours. There can be no excuse for unnecessary duplications or not sharing the learnings of important initiatives like the EURACAN registry which is called "STARTER". If we get the fundamental infrastructure right, the possibilities from the European Health Data Space are very exciting for improving care, research, knowledge and best practice for all tumour types.

To this, and other points, the

European Cancer Organisation's Digital Health Network will publish formal recommendations in September of this year, aided by IBTA contributions.

A Cancer Inequalities Registry to guide our collective efforts and share success

We all know of the persistent presence of gross inequalities in cancer across Europe, spanning the continuum of prevention, detection, treatment and follow up care; between countries and regions; and between groups in society, such as in respect of gender, age, sexuality, ethnicity and socio-economic status. But what role can the EU play in addressing these?

In one of the many novel conceptions of Europe's Beating Cancer Plan it has been pleasing to see the inclusion of a 'Cancer Inequalities Registry' to measure and report these underlying tensions in cancer care and help us all to collectively improve our response to them.

Authority is already being provided to the Organisation for Economic Co-operation and Development (OECD) to take forward the preliminary creation of the Registry. The 'early moving' status of the Cancer Inequalities Registry initiative may be an indication of the personal commitment of EU Health Commissioner Stella Kyriakides to this agenda.

The Inequalities Network of the European Cancer Organisation, of which the IBTA is a highly active participant, has already formed an early set of views on key indicators for inclusion. This includes patient access to multidisciplinary care, levels of health literacy, stages of diagnosis, access to clinical trials, and access to palliative and supportive care. OECD and the European Commission are taking an active interest in these representations and a series of key further meetings of the Network with OECD is being planned for the period between now and the Registry becoming operational. With us all the way will be the important contributions of IBTA on behalf of the brain tumour community.

E.C.O. and the IBTA – working in partnership, putting patients' needs first

In summary, the set of tools that the EU is presently taking forward in the

area of cancer policy hold enormous potential. But like any tools, they need to be deployed and applied well. That is why the European Cancer Organisation is so pleased to be working in such close partnership with the International Brain Tumour Alliance to exchange together, and with EU decision-makers, to help ensure patient needs come first in all policy decisions being undertaken. "More is achieved by working together" is a motif intrinsic to the philosophy of both organisations, and of Europe's Beating Cancer Plan itself. I feel confident the long-term outcomes of Europe's Beating Cancer Plan will prove a testament to that proposition. ■

Stay tuned:

Other collaborations underway between the IBTA and E.C.O. include a policy roundtable on metastatic cancer needs (October 2021) and a forthcoming publication of a new 'Essential Requirements for Quality Cancer Care: Glioma'.

More information about the work of the European Cancer Organisation (E.C.O.) is available on E.C.O.'s website at www.europecancercancer.org

Please join us
in 2021!

Raise awareness of
the challenges of brain
tumours - plan an event
for International Brain
Tumour Awareness Week
2021 (30th October to
6th November)

An interview with Kipling Beardsley, newly-appointed CEO of OurBrainBank



IBTA: Kipling, where did you grow up?

Kipling Beardsley (KB): I grew up in the state of Montana, a very rural part of the US right on the border with Canada. My mom is a nurse which, I believe, is where I got my passion for working in the health field.

IBTA: What was your previous role before coming to OurBrainBank (OBB) as CEO?

KB: Previous to coming to OurBrainBank, I worked for over 25 years in the fields of public health and international development. This experience included everything from very grassroots HIV work with gay men and people who inject drugs, to managing the state-wide HIV response at state health departments, to supporting technical and managerial capacity of civil society and ministries of health in over 25 countries in areas such as policy and advocacy, pandemic preparedness, communicable, non-communicable and chronic disease, and health finance.

IBTA: What led you to want to become involved in this field?

KB: Much like the passion that I see driven by the personal experiences of people with GBM, I became involved in public health as a gay man who, in his 20's, literally lost count of how many friends had died in the HIV epidemic. Public health, and particularly the



Kipling Beardsley

concepts of the social determinants of health, resonated with me because of the perspective that moved beyond the individual to integrate the systems, communities, and other factors such as income and education that must come together to create health. Without this holistic perspective of individual and community well-being, we end up with the health disparities that we see repeatedly.

IBTA: What experiences and learnings from previous work positions are you bringing to your role at OurBrainBank?

KB: During my lifetime, HIV has moved

from terminal to treatable – driven in large part by the power of people living with HIV. I have been inspired by the unrelenting resilience of patients, care teams, and advocates. I have seen how addressing the quality of life is as important as achieving clinical outcomes. I have witnessed the value of the patient perspective in the design, implementation, and evaluation of programs. And I have experienced how stigma and discrimination and barriers to information and treatment drive inequities. This lived experience is now part of my professional and personal DNA and it informs my drive and passion for this work.

IBTA: We realise that it is early days – as you have only recently taken up the post of CEO at OurBrainBank – but what, to date, has given you the most satisfaction from your work at this organisation?

KB: I was able to meet our founder, Jessica Morris, briefly in my first week on the job and it has given me great joy to see how her passion for the patient perspective is at the core of the mission of OBB.

As we learned in HIV, empowering patients to engage in their health care and to advocate for their rights is critical in the fight against GBM. The work OBB is doing to develop a mechanism for individuals living with GBM to track their symptoms will not only empower patients to manage their disease and make decisions based on personal values and priorities, but it has the potential to leverage a relatively small investment in the power of data and collaboration to achieve advocacy and research outcomes that are magnitudes beyond what could be achieved with individual, isolated efforts.

IBTA: A brain tumor is a rare cancer and brings with it some unique challenges. What has struck you so far about these challenges?

KB: I'm struck by how little we know about GBM and the heterogeneity of each

individual's journey with this disease. I'm also struck by the challenges in getting new research and treatment options. These challenges drive OBB's vision for a broad data set that is representative of the breadth of the GBM experience and our mission to support collaborative approaches to data, research, and advocacy.

IBTA: What is the role you would like to see OurBrainBank play in the coming years?

KB: It is an extremely exciting time to be at OBB. We successfully completed a pilot study that proves the concept of engaging patients in reporting quality of life measures and are poised to engage with patients, care teams, advocates, and researchers to improve on this pilot and move to full implementation.

My vision is that OurBrainBank provides quality, representative, prospective data on the experience of people living with GBM. We must make sure that this data is reflective of the experience of everyone living with GBM – from those living near major medical centers to those in small towns like the one I grew up in. And we must make sure that the entire process of data collection, analysis, and dissemination is designed with the engagement of the GBM community and with a goal of identifying

and addressing health disparities.

My hope is that this data provides support to people living with GBM, to help them understand their symptoms, and to know that they are not alone. I also hope that the data donated by patients and their care teams makes research and advocacy more feasible and effective.

IBTA: How do you relax, and do you have a hobby or a sport with which you are involved?

KB: I'd have to say that one of my favorite hobbies or sports is being a New Yorker. New York provides such a wealth of global experiences. Every day is an adventure for me – listening to the languages on the subway, exploring cuisine from around the world, witnessing the stories of people told through the arts, and participating in the day-to-day struggles and joys of fellow New Yorkers.

IBTA: Is there anything else you would like to add?

KB: Thanks for the opportunity to share a part of my story. I'm honored to be standing on the shoulders of Jessica and others who are traveling the GBM journey, I'm grateful for the warm welcome and support I've gotten from this community, and I look forward to our work together. ■

Brain tumours and COVID-19



Between April and May 2020, the International Brain Tumour Alliance (IBTA), as part of its collaborative work with the Society for Neuro-Oncology's (SNO) COVID-19 Task Force, organised a global survey to understand the pandemic-related concerns of brain tumour patients and their caregivers,

with a view to inform future support and service development.

The survey was administered online through more than 120 brain tumour not-for-profit organisations and charities worldwide, as well as through treating physicians. The survey was available in seven languages: English, French, German, Italian, Spanish, Polish and Japanese. One thousand, nine hundred and eight-nine people responded to the survey from 33 countries with representation from different geographic regions including the Americas – North, Central and South – Europe, Africa and Asia/Oceania. Over 30 different types of brain tumours were represented.

Respondents included 1,459 brain tumour patients: 1,284 adults (18 years or older) and 175 paediatric brain tumour

patients (under 18 years old, with the parent's or legal guardian's assistance and consent) and 530 caregivers.

The survey findings – entitled "Brain tumours and COVID-19: the patient and caregiver experience" – were published in August 2020 in the journal *Neuro-Oncology Advances*. A plain language summary of the survey findings was also published by the IBTA. ■

See this link for free access to the IBTA COVID-19 survey paper in *Neuro-Oncology Advances*: <https://doi.org/10.1093/oaajnl/vdaa104>. The plain language summary for this survey is freely available here: <https://theibta.org/ibta-news/ibta-covid-19-survey-published/>

SISAQOL-IMI: generating new international standards for the use of patient reported outcome (PRO) data in cancer clinical trials

Jayne Galinsky

on behalf of Myeloma Patients Europe (MPE) and WECAN (Workgroup of European Cancer Patient Advocacy Networks)



An international multidisciplinary consortium, guided by the European Organisation for Research and Treatment of Cancer (EORTC), has been set up to generate recommendations to standardize the use, analysis, and interpretation of PRO data in cancer clinical trials.

The consortium project - partly funded by the European Commission and partly funded by industry partners who, together make up the Innovative Medicines Initiative or "IMI" - is called SISAQOL-IMI. SISAQOL is the acronym for "Setting International Standards of Patient Reported Outcomes and Quality of Life Endpoints in Cancer Clinical Trials". The International Brain Tumour Alliance (IBTA) has been involved for a number of years in the first phase of the SISAQOL project and continues to be involved during this exciting new phase of SISAQOL-IMI. IBTA Chair Kathy Oliver serves on the SISAQOL-IMI project coordination team.

Kathy said: "The SISAQOL-IMI initiative is a ground-breaking project which will set much-needed international standards for PRO analysis in cancer clinical trials, including those for brain and CNS tumours. It's a very exciting initiative which the cancer patient community should welcome as a significant step forward in improving patient reported outcomes data collection and analysis."

What are PROs?

A PRO (patient reported outcome) is



Jayne Galinsky

information which is directly reported by the patient without the patient's response being interpreted by a healthcare professional or anyone else. Generally, a patient reported outcome can reflect a patient's health and/or functional status and quality of life. PROs are usually reported in response to a treatment regimen to determine how that treatment is affecting a patient, according to that patient's own personal experience of it. PRO "tools" are questionnaires used within clinical trials to gather PRO data.

The data collected from PROs help decision makers, such as those at the

European Medicines Agency (EMA) and US Food and Drug Administration (FDA), understand more about the benefits and risks of new medicines. Clinical trials in cancer are run by universities, pharmaceutical companies, and other organisations. Therefore, different people have different ways of collecting and analysing PRO data. This makes it difficult for decision makers to compare the results of cancer trials easily, consistently and fairly.

The SISAQOL-IMI project was established to address these challenges. Researchers working on SISAQOL-IMI will agree on and publish a set of guidelines on how PRO data should be collected from patients, how it should be analysed, and how it should be presented to people who make important clinical and regulatory decisions in healthcare.

The SISAQOL-IMI consortium is a group of leading researchers and statisticians, individuals from various international cancer and medical societies, advisory and regulatory bodies, universities, the pharmaceutical industry, cancer institutes and - crucially - patient advocacy organizations (represented by the Workgroup for European Cancer Patient Advocacy Networks, WECAN, and led by Myeloma Patients Europe, MPE, one of the WECAN members). Overall, there are 41 stakeholder groups involved in the SISAQOL-IMI project.

Improved cancer clinical trials for patients

The SISAQOL-IMI project is good news for patients taking part in cancer clinical trials as it is anticipated that the outcomes of the initiative will help improve collection of patients' experiences, and capture in a more consistent way important information on treatment risks, benefits and tolerability.

This project, and its generated recommendations, will also be of critical importance to organisations like the European Medicines Agency and the US Food and Drug Administration, as PRO data presented in the same way across trials and cancers will help support fair and informed decision making. This in turn may lead to improved patient satisfaction with medicines and treatments, an increased likelihood of adherence to treatment, higher likelihood of treatment success, and a reduction in health-care costs in the long term.

Patient advocates have been involved in the project from the very beginning of the original SISAQOL initiative, and through WECAN, will continue to be involved in this next phase of SISAQOL-IMI. WECAN's involvement (led by Myeloma Patients Europe), includes responsibility for communication and dissemination of all project findings and ensuring that any messages emerging from the project are published in plain language so they can be read and understood by all.

Findings will also be translated into different European languages.

Researcher perspectives

The SISAQOL-IMI project is being co-led by Dr Andrew Bottomley, Assistant Director and Head of the Quality of Life Department at the European Organisation for Research and Treatment of Cancer (EORTC) in Brussels, Belgium. Speaking about the project, Dr Bottomley said: "The SISAQOL-IMI project will make a real difference to the lives of patients. Patients and their families are not only concerned with curative treatments, but also the psychosocial impacts that accompany cancer and cancer treatment. It is therefore essential that these are systematically captured when evaluating any new therapies, and that they are measured, analysed, presented, and interpreted as accurately as possible."

Dr Ingolf Griebsch, Head of Corporate Market Access Oncology, at Boehringer Ingelheim and SISAQOL-IMI project co-leader said: "Outcomes from this project will help us understand more about the impact of treatment on the lives of patients. PRO data presented robustly across cancers will allow us to examine and compare trial data effectively and with a better understanding of the ways in which patients experience trials and new treatments."

Dr Madeline Pe, Specialist in Quality of Life at the EORTC, said: "We are pleased

to be part of this exciting collaboration working to ensure that PRO data is collected, analysed, and presented in a more robust and meaningful way. Standardising these procedures will help regulators and HTA bodies, as well as health care professionals, and ultimately patients to understand more about treatment options and the impacts that these may have on individuals and families." ■

For more information on SISAQOL-IMI please visit <https://event.eortc.org/sisaqol/>

Get involved

If you would like to be involved in the SISAQOL-IMI project as a patient or caregiver advocate please contact your WECAN patient organisation. You can find a list of the WECAN patient organisations here - <https://wecanadvocate.eu/>. There is a significant amount of work for patient advocates to do, from reviewing smaller projects within the wider SISAQOL-IMI consortium, to helping run educational workshops for patients on PROs. The patient voice will help make the project stronger.

Frequently asked questions (FAQs)

(1) What are the goals of SISAQOL-IMI?

The primary goal of the SISAQOL-IMI initiative is to create international recommendations on how to analyze PRO data in cancer clinical trials. In order to be successful, these recommendations need to be supported by a broad consensus, balancing different needs and requirements. It is hoped that these recommendations and tools such as how to define clinically meaningful change in PROs; which analysis set to use when analysing the PRO data; and how to handle intercurrent events such as deviation from protocol treatment in the analysis of PROs, will facilitate the analysis of PRO outcomes and result in more reliable findings, improved interpretability and faster dissemination of data that stem from a higher quality use of statistical methods.

(2) How is SISAQOL-IMI funded?

SISAQOL-IMI is a public-private partnership. This means that the project is funded by both the Innovative Medicines Initiative (IMI) - <https://www.imi.europa.eu/>, with funding from the European Union, and also by EFPIA (European Federation of Pharmaceutical Industries and Associations) - <https://www.efpia.eu/>. Joint funding means that projects can be collaborative and involve a wide range of stakeholders in a consortium.

(3) What is a consortium?

A consortium is a group working together to achieve a common goal. In the case of SISAQOL-IMI, this means creating

continued ►

recommendations for the use, interpretation, and analysis of PRO data in cancer clinical trials. Decisions made by the multistakeholder consortium comprising SISAQOL-IMI regarding what the final recommendations will be are made by consensus (general agreement).

(4) How long is the SISAQOL-IMI project?

SISAQOL-IMI recommendations will be developed over four years. A consensus meeting will be organized each year to arrive at a general agreement among the stakeholders for the PRO analysis recommendations, but also to communicate project progress and results as it progresses.

(5) How is SISAQOL-IMI structured?

SISAQOL-IMI is organised into five scientific work packages (WP 2, 3, 4, 5 and 6), and three cross-cutting work packages (WP 1, 7 and 8). The scientific work packages will suggest recommendations on PROs based on their scientific work such as literature reviews and expert evaluations. The recommendations will then be discussed in the consensus meetings. The recommendations endorsed by all SISAQOL-IMI stakeholders will be shared with the general public through various channels including the SISAQOL-IMI website, reports, publications and workshops.

WP 2 will focus on the use of PROs in randomized cancer clinical trials (RCTs) whereas WP 3 will explore the feasibility of formulating recommendations for single-arm studies which are becoming increasingly popular when RCTs are not preferable. WP 4 will develop visualization tools to present PRO findings in a way that is easy for different stakeholders to understand, particularly patients. WP 6 will provide recommendations on how to better define clinically meaningful change in PROs for different trial objectives. WP 5 will organize the validation of the proposed recommendations via pilot case studies.

Two of the cross-cutting work packages - WP 1 and WP 7 - will be responsible for management and coordination of SISAQOL-IMI, and ensuring that the recommendations are based on a consensus and that relevant key stakeholder groups are represented.

Crucially, WP8 will support all scientific WPs at all stages of their work by bringing in the patient's perspective. The overall aim of WP 8 is to facilitate wide and clear dissemination of the SISAQOL-IMI activities and to maximize the uptake of the recommendations by all stakeholders. This will lead to better exploitation of data gathered from patients to inform clinical benefit analysis, decision-making by patients, clinicians and regulators, and to improve the safety, and tolerability of new treatments for cancer.

NOTE: The above article (including the FAQs and other text) reflects the author's view and neither IMI nor the European Union, EFPIA, or any Associated Partners are responsible for any use that may be made of the information contained therein. This project has received funding from the Innovative Medicines Initiative 2 Joint Undertaking (JU) under grant agreement No 945052. The JU receives support from the European Union's Horizon 2020 research and innovation programme and EFPIA.

Philippine lay forum on brain tumours

Dr Juliette Batara, a neurologist/ neuro-oncologist working at St Luke's Medical Center, Quezon City and Global City in the Philippines wrote to let the IBTA know that the Philippine Society for Neurooncology, the University of the Philippines and Philippine General Hospital held a Lay Forum on Brain Tumors on 30th October during the 2020 International Brain Tumour Awareness Week.

The forum was held on Zoom and Facebook Live and covered the following topics relating to brain tumor treatment: neurosurgery, chemotherapy, radiotherapy, depression and anxiety

and herbal/ alternative medicine (with the title "Is Herbal Medicine OK?").

Lectures aimed at brain tumour patients, caregivers, families and the general public on the above topics were given, followed by an hour for questions from the audience.

In addition, a book written and published by the family of a former brain tumor patient in the Philippines - *Life With A Brain Tumor* by Adrienne Dy, MD and Enrico Leyeza - was also promoted.

To view a recording of the lay forum please visit <https://www.facebook.com/PGH.adultneuro/videos/1798715916943050>



"A Brain Tumour and Me" -

new IBTA podcast series to air during

International Brain Tumour Awareness Week 2021



Broadcaster Graham Seaman (left) interviews IBTA podcast guest Dr Stuart Farrimond (right)

During the 2021 International Brain Tumour Awareness Week (Saturday, 30th October to Saturday, 6th November), the International Brain Tumour Alliance (IBTA) will begin to release a new series of inspirational podcasts.

The series is entitled: "A Brain Tumour and Me". It explores how a brain tumour has prompted individuals to look at their lives in a different light and dramatically change direction or successfully take on challenges they never previously anticipated. The podcast will feature people who have been diagnosed with a brain tumour as well as those who work professionally with brain tumour patients in the field of neuro-oncology.

Our podcast series premieres with a 20-minute programme featuring Dr Stuart Farrimond in the United Kingdom. "Dr Stu" as he is called, is a medical doctor turned

food scientist and best-selling author following his diagnosis of a malignant brain tumour in 2008.

After his diagnosis, Dr Stu had to leave medical practice. He then retrained as a further education health sciences lecturer where he discovered a passion for science communication. Today Dr Stu regularly appears on TV and radio. As well as his series of highly popular books for Dorling Kindersley (DK), he has written for publications including *the Independent*, *Daily Mail* and *New Scientist*. In our IBTA podcast series, Dr Stu reveals the journey that took him from being a hospital doctor to a highly successful and much-loved science and health writer, media presenter and educator.

Our IBTA podcast producer/broadcaster is Graham Seaman of Graham Seaman Media. With over 35 years of commercial

and BBC radio production and presentation experience, Graham has interviewed a wide range of celebrities like the former British Prime Minister, Sir John Major. Graham said: "For me, though, everyone's a celebrity, everyone has a story to tell and quite often they don't even know it themselves until they're asked the right questions."

We're thrilled that Graham will be producing our new IBTA podcast series, "A Brain Tumour and Me". And we very much look forward to learning more about our truly amazing podcast guests. We do hope you will join us and listen in! ■

Watch the IBTA monthly e-News for further announcements of our podcast series, "A Brain Tumour and Me". To subscribe to the IBTA e-News, please visit: <https://theibta.org/our-publications/#e-News>

For more information on Dr Stu and Graham Seaman Media, please see: www.stuartfarrimond.com and www.grahamseamanmedia.co.uk



The CEANNE experience in Brazil – closing the gap in neurosurgical care between public and private healthcare patients

Gustavo R Isolan MD

Neurosurgeon, founder and director CEANNE; Professor of Medicine Faculdade Evangelica Mackenzie de Paraná, Porto Alegre, Brazil

Rafael Roesler PhD

Department of Pharmacology, Institute for Basic Health Sciences, Federal University of Rio Grande do Sul, Porto Alegre, Brazil

Brazil is an enormous country with 213 million inhabitants (1) and has one of the largest and most complex public healthcare systems in the world, known locally as SUS (Unified Health System, Sistema Único de Saúde). Healthcare under this system is cost-free to patients, from medication to organ transplants. However, because SUS covers many areas that are isolated and quite socio-economically heterogeneous, it is often unable to provide treatment. Bureaucratic and financial obstacles further prevent all Brazilians from receiving “comprehensive and universal” access to healthcare as stipulated in the Brazilian Constitution.

Healthcare and challenges

This has led the wealthiest Brazilians to seek private healthcare plans, and also to large numbers of legal cases brought by individual patients who intend to force the hand of SUS. These cases press for the latest chemotherapy drugs not currently available from national healthcare, for highly complex surgeries, and for new technologies. In neurosurgical oncology, many such cases seek intraoperative neurophysiological monitoring and newer chemotherapy agents. In 2017 alone there were 95,700 healthcare claims filed in Brazilian courts (4). These lawsuits drain government resources that would be better spent on healthcare programs,



Dr Gustavo R Isolan, founder and director of CEANNE in Brazil

especially basic healthcare programs such as chronic disease prevention and vaccination campaigns, for example. In 2016, healthcare lawsuits brought against SUS drained US\$260 million from the federal budget.

Regarding the hunger for private plans, the 2019 National Healthcare Survey revealed that in the previous year 28.5% of Brazilians had a medical or dental plan, totaling nearly 60 million people (5). Even with this demand and a network of excellent private hospitals, seven out of ten Brazilians are still fully dependent



Dr Rafael Roesler

on SUS. As already noted, however, SUS is not able in many situations to furnish proper care to all patients.

Large hospitals in the Brazilian public healthcare system treat neurosurgical patients, and most are university hospitals. However, they are unable to effectively meet all the demands of patients with brain tumors, especially those from rural areas. Even if neurosurgeons are stationed in these areas, hospitals often do not have the proper neurosurgical instruments, such as ultrasonic aspirators, or multidisciplinary teams capable of treating patients with



Training seminar on palliative care for neurological patients with employees from various areas at Hospital Centenário de São Leopoldo

complex brain tumors, including eloquent area gliomas or certain skull base tumors.

The state of Rio Grande do Sul had a population 11.4 million in 2020 (6) and 18 public hospitals accredited by the government to perform oncological neurosurgeries (7). However, some of these hospitals did not have on hand the necessary instrumentation for treating patients. According to the state’s regulatory system, patients have no choice but

to accept treatment exclusively from a specific hospital based on their city of residence. In 2020, many patients were sent for treatment to hospitals that did not have the minimum conditions for complex procedures such as neurosurgery. Such conditions potentially create and maintain wide disparities in the quality of care that brain tumor patients receive from SUS.

With the aim of reducing this disparity and providing adequate hospital



Training seminar on telestroke and telehealth with employees at Hospital São Francisco de Paulo in the city of Cruz Alta

infrastructure for the treatment of patients with highly complex neurosurgical diseases, a group of neurosurgeons created CEANNE (the Center for Advanced Neurology and Neurosurgery) in 2012.

About the CEANNE project

CEANNE is a private company that, although not recognized in Brazil as a non-profit or NGO, operates within the public health system to bring state-of-the-art neurosurgery to SUS patients, and to predominantly low-income patients. For the several dozen neurosurgeons and neurologists at CEANNE, their mission is to treat patients with highly complex neurosurgical cases transferred from under-equipped and overburdened public hospitals and to create an island of excellence in the field of neurosurgical care.

Programs and strategies we have developed and observed over the last nine years serve as the foundation for the solid results we obtain with patients. Among these are:

- Equip a hospital we work in with adequate neurosurgical instrumentation, including microscope, ultrasonic aspirator, and intraoperative neurophysiological equipment monitoring for brain mapping;
- Assemble a team of professionals from various areas and with a broad variety of training and experience, such as spine, vascular, oncology, skull base surgery, etc;
- Use telehealth to discuss cases among professionals at various medical centers and select the most experienced neurosurgical team to treat the case at hand;
- Have a neurosurgeon either on duty at the hospital or on call within 30 minutes travel time for any emergencies;
- Maintain a secretary that will be available for direct communication with the patient and their families;
- Conduct training seminars for professionals in other areas of the hospital, especially for nurses and general practitioners who work in the hospital’s emergency room;
- Follow protocols previously established by the team for each disease. For example, every patient with a tumor in the language area of

continued ➤

the brain must undergo awake surgery with cortical and subcortical mapping. Also, every patient with vestibular schwannoma must have facial nerve monitoring in surgery;

- Offer an average of 500 elective consultations per month in each hospital for neurological and neurosurgical patients;
- Have a team of general practitioners assess the preoperative and clinical conditions of patients;
- Foster constant improvement among fellow neurosurgeons in all of the neurosurgical specialties. For example, three fellow neurosurgeons are currently working on their master's and three on their doctorates in the area of epigenetics of membrane markers of gliomas and medulloblastomas in the graduate program at the Faculdade Evangélica do Paraná and in partnership with the Brazilian startup Epigenica and CEANNE. In 2019, four neurosurgeons from CEANNE took part in the 8th edition of the Brazilian-American Hands-on Course in Skull Base Surgery offered by Professors Antonio Bernardo, Ricardo Lopes and Gustavo Isolan at the Cornell University Microsurgery Laboratory in New York City.

Working in hospitals in the cities of Rio Grande, São Leopoldo, Canoas, Viamão, Cruz Alta and Uruguaiana, the 42 neurosurgeons of CEANNE operated on more than 5,000 neurosurgical patients referred by SUS between 2012 and 2020. Approximately 20% of these patients had brain tumors. All patients were operated on by a group of subspecialists, which presumably contributed to safer procedures. In addition, more than 70,000 elective SUS neurology and neurosurgery consultations were conducted by the medical team. Analyzing 55 microsurgical resections of insular gliomas by the same neurosurgeon (GRI) in different hospitals, there were no statistically significant differences in regard to extent of resection, morbidity, or mortality, between surgeries performed in private hospitals and those performed in public hospitals with a CEANNE program.

We believe that this type of organization and cooperation can greatly benefit patients from areas lacking adequate infrastructure for complex



Brain mapping performed on a musician with a glioma in the motor and pre-motor area at Hospital Municipal de Canoas



Setting up a neurosurgical microscope at the Hospital Centenário de São Leopoldo

neurosurgical procedures, and especially those in underdeveloped regions.

In Brazil, underfunding SUS often results in financial transfer to outsourced service providers such as CEANNE, sometimes

after delays of several months. This is why this project was discontinued in certain hospitals mentioned above. Even so, CEANNE has operated on an average of 50 patients each month in Southern Brazil. ■

References

1. https://www.ibge.gov.br/apps/populacao/projecao/box_popclock.php
2. <https://politica.estadao.com.br/blogs/estadao-verifica/publicacao-pro-sus-utiliza-dados-corretos-ao-comparar-brasil-com-outros-paises/>
3. <https://ambitojuridico.com.br/cadernos/direito-constitucional/o-direito-a-saude-na-constituicao-federal-de-1988/>
4. <https://www.insper.edu.br/knowledge/direito/judicializacao-da-saude-dispara-e-ja-custa-r-13-bi-a-uniao/>
5. <https://agenciabrasil.ebc.com.br/saude/noticia/2020-09/pesquisa-diz-que-597-milhoes-de-pessoas-tem-plano-de-saude-em-2019>
6. <https://www.ibge.gov.br/cidades-e-estados/rs.html>
7. <https://saude.rs.gov.br/upload/arquivos/carga20180834/30163429-cibr306-18.pdf>

The Brain Tumour Patients' Charter of Rights

The Brain Tumour Patients' Charter of Rights is intended to address brain tumour inequalities across countries. It is also meant to simulate debate and discussion. We hope that the *Charter* goals are shared by us all, whether we are brain tumour patients, caregivers, advocates, healthcare professionals or policymakers.

The *Charter* - which was launched last year around the world - is reproduced for our readers on the following pages. We are delighted to also include a list of the over 90 *Charter* supporters to date and we always welcome more organisations to support the aims of the *Charter*.

Please let us know if you would like to come on board with this by contacting kathy@theibta.org

The *Charter* is designed to be relevant across the globe and to this end, we at the IBTA have also started a programme of translating it into as many languages as possible. This will maximise the impact of the *Charter* and help broaden accessibility to it.

To date, the *Charter* has been translated into 12 languages: Catalan, Chinese (Traditional), Chinese (Simplified), Danish, French, German, Greek, Italian, Japanese, Polish, Portuguese and Spanish. Urdu,

Norwegian and Hindi are in the translation pipeline. In fact, by 2022, we hope to be able to offer at least 22 translations of *The Brain Tumour Patients' Charter of Rights* - so 22 in 2022!

To further maximise dissemination and use of the *Charter* around the world, we warmly welcome volunteers to translate the *Charter* document into additional languages not yet covered. Guidelines for translators can be downloaded from the IBTA website at www.theibta.org. If you are interested in helping us translate the *Charter*, please contact kathy@theibta.org. We'd love to hear from you! ■





THE BRAIN TUMOUR PATIENTS' CHARTER OF RIGHTS

THE BRAIN TUMOUR PATIENTS' CHARTER OF RIGHTS

PURPOSE OF THIS CHARTER

To achieve the best possible health and quality of life outcomes for adults and children living with a brain tumour. To represent an aspirational ideal against which quality standards, policies and practices are developed, monitored and delivered.

INTRODUCTION

There are a number of documents dealing with patients' rights, some of which relate to the rights listed here. This Charter has been drafted from the point of view of the brain tumour patient and caregiver with particular consideration for the difficulties which can arise while living with a brain tumour. This Charter has been created through a multi-stakeholder, collaborative and iterative process and is a living document, subject to annual review.

It is hoped that this Charter will have worldwide relevance. We are mindful that many countries lack basic health, research and manufacturing facilities and the specialists and treatment centres with the capacity to deliver the most modern scientific evidence-based care for brain tumour patients. The Charter therefore represents an aspirational ideal which we should work towards and we hope and expect that it will prompt productive discussion and debate to help initiate positive change.

Importantly, the Charter provides a detailed framework for the achievement of policy objectives which brain tumour patient advocacy organisations can use to support their efforts. It can also be used by individual patients and caregivers to underpin the things that matter to them on their brain tumour journeys. The Charter is also meant to be a positive tool that can be used by other sectors of the international brain tumour community.

The Charter can provide everyone with an aspirational framework for improving healthcare systems and communications – goals which we hope will help reduce inequalities from country to country. The Charter is not intended to detract from or criticize the sterling work being carried out every day around the world by researchers, healthcare professionals and others.

We invite those living in developing countries – where many of the aspects of this Charter will not be easily attainable – to select those aspects of this document which are achievable in their own regions and to focus on those to help secure better outcomes for brain tumour patients.

While asserting these rights we acknowledge that no rights can exist in human society without responsibilities.

NOTES

- 1. This Brain Tumour Patients' Charter of Rights is not a guarantee of these rights, nor is it legally binding.*
- 2. This is the current version of The Brain Tumour Patients' Charter of Rights but as a living document, it is also subject to annual review, and a procedure for the Charter's further evolution will be established.*
- 3. Please see the attached appendix to this document which lists the brain tumour charities and not-for-profits, professional neuro-oncology societies and other organisations who have ratified The Brain Tumour Patients' Charter of Rights and given permission for their logos to appear on this document.*

1. ACKNOWLEDGEMENT AND RESPECT

I shall have the right to:

- a) access health care designed to reduce the burden of my brain tumour
- b) be acknowledged as a person living with a brain tumour
- c) be treated as an individual
- d) describe myself - whether I am an adult or a child living with a brain tumour - with whatever terminology I feel comfortable with
- e) be heard and acknowledged, even if the health care professional does not necessarily agree with my position or perspective
- f) be respected as a significant partner in my own care and an expert in my own needs and experience
- g) not be discriminated against in my community or my workplace or indeed anywhere at any time because I have a brain tumour
- h) maintain hope and to be supported in that hope by my medical team and others responsible for my care, no matter what the diagnosis and prognosis

2. APPROPRIATE INVESTIGATION OF SIGNS AND SYMPTOMS

I shall have the right to:

- a) information and education about brain tumours
- b) my concerns about my health to be investigated promptly by doctors with appropriate training and experience in neuro-oncology, neurology, neuro-surgery and psychosocial health.
- c) a clear explanation of medical imaging done of my brain and brain tumour and the different scanning and assessment techniques and what they can and cannot tell us

d) a clear explanation of the options for treatment of my brain tumour, e.g. surgery, radiation, chemotherapy, clinical trials etc, including the associated risks

e) my tissue/biopsy sample to be analyzed by an experienced neuro-pathologist using validated pathological/diagnostic tests (including biomarker assays) in order to provide me with a correct diagnosis

f) provide informed consent about the use of my resected tumour tissue and, if I have donated/stored brain/tumour tissue or any other bio-specimen for research or other purposes, to know if my tissue sample may be accessed for future treatment decisions and research

3. A CLEAR, COMPREHENSIVE, INTEGRATED DIAGNOSIS

I shall have the right to:

- a) a timely referral to a specialist health care provider of my choice
- b) receive a prompt and accurate diagnosis (based on an integrated analysis of my tumour tissue using the World Health Organization's most up-to-date classification of brain tumours, and a clinical presentation) which should be conveyed to me in a clear and compassionate manner
- c) ask questions about my diagnosis and receive appropriate answers in terms I can understand
- d) be accompanied to my diagnosis appointment and any subsequent appointments during the course of my treatment by a family member, close friend or other designated caregiver
- e) an interpreter, if the diagnosis is delivered to me in a language in which I am not fluent
- f) be proactively involved in all of the decision-making processes relating to my diagnosis and subsequent care
- g) take notes in my medical appointments for the sake of clarity and as an aide memoire. Further - but only if I first get all necessary permissions to do so - to record my medical appointments.

h) request and access other opinions at any stage of my care and treatment and to be informed by a specialist if he/she believes they are unable or unwilling to perform an operation, or administer a therapy

i) be given as detailed a prognosis as possible, if requested, which includes information regarding quality of life, side effects of treatment, potential for late effects of treatment and probability of survival

j) a complete copy of all the notes taken in relation to my diagnosis by my medical providers that go into my medical records

4. APPROPRIATE SUPPORT

I shall have the right to:

a) clear, unbiased, honest, comprehensive and timely information that will help me make the difficult decisions with which I will be faced. I also have the right to challenge this information and seek clarification about anything that I do not understand

b) access decision-making tools to enable me to make the right choices for my situation

c) support from a care coordinator or brain tumour journey navigator (i.e. a specialist nurse, social worker or other trained person)

d) be offered information on legal issues that I may need to consider, for example power of attorney, guardianship of children, living wills, advance directives, etc

e) be offered appropriate information about returning to work or school and the laws in my country that govern employing or educating people with disabilities

f) participate in a brain tumour support group if one exists in my local area, attend one virtually or have the opportunity - if I wish - to establish one if it doesn't yet exist

g) be told about local, regional and international brain tumour patient advocacy organisations to whom I can turn for advice and further support

5. EXCELLENT TREATMENT AND HIGH-QUALITY FOLLOW-UP CARE

I shall have the right to:

a) be informed about all available relevant treatment options, in my country of residence, whether (or not) the cost of delivering such treatments are reimbursed by insurance or other third parties

b) share with my treating doctors the decision-making process in selecting the best treatment/s for me, taking into account the level of risk I am prepared to take

c) access treatments based on need – not on my ability to pay for it

d) receive the accepted international standard of brain tumour care, regardless of my age, race, economic background, disability, beliefs or gender

e) receive emergency treatment to stabilise my condition at any point in my brain tumour journey

f) continuity of care from the moment of diagnosis through treatment, recovery, disease progression, long-term survival and end of life. If I am a pediatric patient, continuity of care also includes transitioning to adult follow-up care.

g) be treated in a healthy and safe environment where quality standards are imposed, monitored and met

h) have my medical treatment conducted in accordance with the highest standards of ethical practice.

i) ask for and be provided with copies of all notes and data which go into my medical record, including radiology reports, pathology reports, genetic analyses, etc., as well as digital copies or film copies of all of my scans, and to be recognised as the 'owner' of these records

j) multidisciplinary care, which may include - apart from my core medical team's help - support from other specialists such as physiotherapists, speech and language therapists, psychosocial therapists, social workers, occupational therapists and others

k) be informed if clinically-relevant delays in my treatment are expected and to be informed of alternative service providers who may be able to provide treatments sooner

l) review with my doctor the possibility of using other treatments, experimental or otherwise, in addition to (or instead of) the standard of care

m) be fully informed of all proposed treatments, their benefits and risks and, where relevant, the costs involved

n) refuse or withdraw from treatments, tests, scans and investigations without sanction or vilification

o) be told about relevant, appropriate clinical trials available in my current treatment facility and offered a place if I meet the inclusion/exclusion criteria, or be directed to the contact details for a trial taking place elsewhere for which I might be eligible

p) be fully informed of the benefits and risks involved for me and to have sufficient time, without pressure, to consider participation (or not) in a clinical trial, experimental procedures or investigational programs

q) have my trial participation, should I enroll in such a study, acknowledged and appreciated and be advised of the final outcome of the trial

r) regularly scheduled follow-up appointments and appropriate scanning and tests if I have completed treatment for my brain tumour

s) be treated by an expert health care provider for follow-up. If I am a pediatric patient, this will include being treated by an expert health care provider familiar with the late effects of treatment.

6. THE CARE RELATIONSHIP

I shall have the right to:

a) access an up-to-date contact list of neurosurgeons, radiation oncologists, neuro-oncologists, neurologists and other specialists in my area/country, as needed

b) be provided with the name and contact details of a knowledgeable staff member at

my treating facility who may be able to answer urgent questions out of hours and at times other than scheduled consultations

c) express my opinion or complain without fear of retribution if I receive unsatisfactory care at an institution. I shall also have the right to be given information on the means of expressing this opinion/complaint to management level staff and to expect my complaints to be investigated and the findings conveyed to me in a timely and comprehensive manner

d) challenge my doctor's opinion in a respectful manner and expect the same respect in return

7. SUPPORTIVE/PALLIATIVE CARE

I shall have the right to:

a) receive high quality, fully integrated, multidisciplinary early palliative care which encompasses symptom management, pain relief, psychosocial support, rehabilitation and social and spiritual support

b) receive optimal medication to relieve the symptoms and side effects of my brain tumour and its treatments such as pain, nausea, seizures, etc

8. REHABILITATION AND WELL-BEING

I shall have the right to:

a) access rehabilitation programmes (including speech and language therapy, occupational therapy, neuro-psychological therapy and physical therapy) to address cognitive, behavioural and physical deficits resulting from my brain tumour so that I can maximise my independence and recapture my ability to function as normally as possible

b) information about benefits funding (where available) to ease financial burdens

c) access wellbeing programs specific to my situation as a survivor taking into account my particular, individual needs (including family, employment, financial and psycho-social requirements)

9. MEDICAL INFORMATION AND PRIVACY

I shall have the right to:

- a) have my brain tumour properly registered in my country’s (and international) cancer registration records whether my brain tumour is so-called ‘benign’, low grade or high grade
- b) my own personal physical space and the maintenance of dignity through all tests, investigations, treatments and procedures
- c) have conversations with medical and other professionals about my health and wellbeing which remain private between us
- d) wear appropriate clothing during treatment and care to protect my privacy and minimise embarrassment
- e) keep medical information about myself from being disclosed to other parties without my permission
- f) decide with whom, when and where to share information about my health

10. APPROPRIATE END-OF-LIFE OPTIONS AND CARE

I shall have the right to:

- a) discuss all available end-of-life care options, or be referred to other doctors who are willing to discuss them with me at any point in my brain tumour journey
- b) my primary cause of death being accurately reflected in government records as a brain tumour if such is the case
- c) the proper and appropriate quality and level of care that I decide is right for me as I approach the end of my life
- d) my dignity, and to compassion and respect from others
- e) express my wishes as to my preferred place of death, for example in hospital, at home, in a hospice, etc

- f) advance care planning
- g) donate any part of my body, including my brain and tumour tissue samples, to research or to refuse to do this
- h) make my own end-of-life decisions and for these to be respected as far as they can be within the current laws of the country in which I am receiving treatment and/or care

THE BRAIN TUMOUR PATIENTS’ CHARTER OF RIGHTS DRAFTING COMMITTEE:

Kathy Oliver, International Brain Tumour Alliance (IBTA); Gordon Oliver, International Brain Tumour Alliance (IBTA); Barrie Littlefield, (formerly of) Cure Brain Cancer (Australia); Kristina Knight, (formerly of) National Brain Tumor Society (USA); David Arons, National Brain Tumor Society (USA); Danielle Leach, National Brain Tumor Society (USA)



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APPENDIX
THE BRAIN TUMOUR PATIENTS’
CHARTER OF RIGHTS

The following organisations* have ratified the Charter and support its aims:



*Organisations listed in alphabetical order



Melanoma Patient Network Europe



The Brain Tumour Patients' Charter of Rights is a living document. If your organisation would like to support the Charter please contact kathy@theibta.org If you would like to volunteer to translate The Brain Tumour Patients' Charter of Rights into another language, please contact kathy@theibta.org Guidelines for Charter translators can be found at <https://theibta.org/charter/>

Charter document design: Edwina Kelly · edwina@edwinakellydesign.co.uk

Brain tumour patient and caregiver advocacy, support, fundraising and information organisations and initiatives

AUSTRALIA

ACT Brain Tumour Network

Email bttaa@shout.org.au
or call Susan on 0404255156

Adult Brain Cancer Support Association

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.bttaa.org.au

Brain Tumour Association Western Australia

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

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

Geny and Nancy Pencer Brain Tumor Centre

<http://www.pencerbraintrust.com/>

Meagan's HUG

<https://www.meaganshug.com/>

Tali's Fund

www.taldoron.com

CAYMAN ISLANDS

Brain Tumour Foundation (Cayman Islands)

"The Forgotten"

<https://www.facebook.com/pg/bftcaymanislands/posts/>

CROATIA

Croatian Brain Tumor Association - GLIA

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

ARTC Paris

<http://www.artc.asso.fr/>

ARTC Sud

www.artcsud.fr

ARTC Toulouse – Midi Pyrenees

<http://www.artc.asso.fr>

Association Léa Princesse Eternelle

<http://leapourlavie.free.fr/>

GFME Glioblastoma Foundation

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

GERMANY

Deutsche Hirntumorhilfe eV

www.hirntumorhilfe.de

Gemeinsam gegen Glioblastom

www.gemeinsamgegenglioblastom.eu

yeswecan!cer

<https://yeswecan-cer.org/>

INDIA

Brain Tumour Foundation of India

www.braintumourindia.org

BTSG Awareness Foundation India

(Brain Tumor Support Group and Awareness Foundation)

www.btsfoundation.in

IRELAND

Brain Tumour Ireland

<http://www.braintumouireland.com/bti/>

The Irish Brain Tumour Support Group

www.braintumoursupport.ie

ITALY

Associazione Italiana Tumori Cerebrali ONLUS

<http://www.tumorocerebrali.it/>

BrainLife

www.brainlife.org

Brainy

www.associazionebrainy.com

Il Fondo di Gio ONLUS

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/>

Oscar's Angels Italia

<https://www.oscarsangelsitalia.com>

JAPAN

Japan Pediatric Brain Tumor Network

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

Lithuanian Brain Tumour Patients

and their Caregivers Society

Phone: +370 37 326694

NETHERLANDS

Hersentletsel.nl

<http://www.hersenletsel.nl>

Hersentumor.nl

<http://hersentumor.nl/>

Hersentumorfonds

<https://hersentumorfonds.org/>

Hersentumoren.info

<https://hersentumoren.info/>

STOPhersentumoren.nl

www.stophersentumoren.nl

NORWAY

Hjernesvulstforeningen

www.hjernesvulst.no

PAKISTAN

Brain Tumour Foundation of Pakistan

In partnership with the Pakistan Society of

Neuro-Oncology

www.braintumour.pk

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

SWEDEN

Swedish Brain Tumor Association

(Svenska hjäntumörföreningen)

www.hjamtumoreningen.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 Derneği

(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

Andrew McCartney Trust Fund

www.andrewmccartneyphotos.co.uk

Anna's Hope

www.annashope.co.uk

Astro Brain Tumour Fund

www.astrofund.org.uk

Brain and Spine Foundation

www.brainandspine.org.uk

Brain Tumour Action

www.braintumouraction.org.uk

Brain Tumour Research

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

Brain Tumour Support Group -

St Thomas' Hospital, London

<http://www.guysandstthomas.nhs.uk/our-services/cancer/cancer-types/brain/patients.aspx>

Brainstrust

www.brainstrust.org.uk

Brainwaves Brain Tumour Support Group

<http://www.brainwavessg.co.uk/>

Brainwaves NI (Northern Ireland)

www.brainwaves-ni.org

British Acoustic Neuroma Association - BANA

www.bana-uk.com

Clowns in the Sky

<http://www.clownsinthesky.org/>

Headcase

www.headcase.org.uk

Katie McKerracher Trust

www.katiemckerrachertrust.co.uk

Levi's Star

<http://www.freewebs.com/levistar/>

Naseem's Manx Brain Tumour Charity

<http://www.naseemsmanxbraintumourcharity.co.uk/>

PPR Foundation

<http://www.thepprfoundation.com/>

Spinal Cord Tumour Forum

www.spinalcordtumour.org.uk

Taylan's Project

www.taylansproject.com

Teenage Cancer Trust

www.teenagecancertrust.org

The Brain Tumour Charity

www.thebraintumourcharity.org

Thorne Mason Trust

<http://www.thomemasontrust.co.uk/>

Tuberous Sclerosis Association

www.tuberous-sclerosis.org

UNITED STATES

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

BT Survivor Online Group
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

Childhood Brain Tumor Foundation
www.childhoodbraintumor.org

Children's Brain Tumor Foundation
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.drmarierose.org/
<https://www.facebook.com/drmamierosefoundation/>

EndBrainCancer (Chris Elliott Fund)
www.EndBrainCancer.org

Ependyaparents online support group
<http://braintrust.org/groups/ependyaparents/>

Epidemoid Brain Tumor Society (Online)
<http://epidemoidbraintumorsociety.org/>

Florida Brain Tumor Association
<http://www.floridabraintumor.com/homepage.htm>

Gray Matters Foundation
www.graymattersfoundation.com

Head for the Cure Foundation
www.headfortheure.org

Healing Exchange Brain Trust
<http://braintrust.org>

Jeffrey Thomas Hayden Foundation
www.jthf.org/

Just One More Day:
<http://dipg.blogspot.co.uk/>

Kevin J Mullin Memorial Fund for Brain Tumor Research
www.lemonhead.org/

Kortney Rose Foundation
<http://thekortneyrosefoundation.org/>

Making Headway
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

Matthew's Miles
<http://www.matthewsmiles.org/>

Meningioma Mommas
www.meningiomamommas.org

Michael Quinlan Brain Tumor Program/ Brain Injury Association of Kentucky
www.biak.us

Monmouth and Ocean County Brain Tumor Support Group
www.njbt.org/startMOCBTSG.cfm

Musella Foundation for Brain Tumor Research and Information, Inc.
www.virtualtrials.com

National Brain Tumor Society
www.braintumor.org

Nick Gonzalez Foundation for Brain Tumor Research
<http://thenickgonzalesfoundation.org/>

Pediatric Brain Tumor Foundation
<http://www.curethekids.org/>

ROC On! Run Over Cancer
<https://www.facebook.com/pages/category/Nonprofit-Organization/ROC-on-Run-Over-Cancer-310235803819/>

San Diego Brain Tumor Foundation
www.sdbtf.org

Sontag Foundation
<https://sontagfoundation.org>

Southeastern Brain Tumor Foundation
<http://sbtbf.org/>

Students Supporting Brain Tumor Research (SSBTR)
<http://www.ssbtr.org/>

Team Billy
www.teambilly.org

The Caroline Fund
<http://www.carolinefund.org>

The Cure Starts Now Foundation
www.thecurestartsnow.org

The Tanner Seebaum Foundation
www.tannersfoundation.org

Tug McGraw Foundation
<http://www.tugmcgraw.org>

Voices Against Brain Cancer
www.voicesagainstbraincancer.org

ZIMBABWE
Zimbabwe Brain Tumor Association (ZBTA)
<https://www.facebook.com/Zimbabwe-Brain-Tumor-Association-225796887464934/>



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INTERNATIONAL BRAIN TUMOUR AWARENESS WEEK

30 October - 6 November 2021

The IBTA requires no financial commitment from your organisation to be a supporter.
Contact kathy@theibta.org

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www.theibta.org

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