

## Brain Tumour

You are not alone on this journey...

Ballerina Anna Mott: a brain tumour left her paralysed and blind. But now she's dancing again.

This courageous and inspirational young woman shares her story

IMMUNOTHERAPY FOR BRAIN TUMOURS

GBM AGILE TRIAL:
 an innovative
 approach to acquiring
 new knowledge faster

IMPORTANT NEW LOW GRADE GLIOMA AND RARE PEDIATRIC BRAIN TUMOUR REGISTRIES

 ARTICLES ON ADULT AND PEDIATRIC BRAIN TUMOURS





### **Walk Around the World for Brain Tumours!**

Organise a sponsored walk to raise awareness of and funds for more research and support.

Walks can be done anytime between

### 1 January & 31 December 2016

The IBTA doesn't want any of your funds raised. These should go to local brain tumour support groups or relevant research institutions. We would like you to symbolically "donate" to the IBTA only the mileage achieved by you on your walk. Walks can also take place during the International Brain Tumour Awareness Week (22 – 29 October 2016) when groups and individuals around the world will organise scientific meetings, patient conferences, TV interviews, press releases, etc in order to raise awareness about brain tumours. For your organisation or group to be a "supporter" of the "Walk" and "Week" please contact the IBTA Chair as below. The IBTA requires no financial commitment or fee to be paid to us by you. All we are asking for is your enthusiasm in supporting and promoting these events and for allowing us to add your name to our list of supporters.



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

### WORLD EDITION 2016/2017

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# 17<sup>th</sup> International Symposium on Pediatric Neuro-Oncology



### Dear Colleagues and Friends of the Pediatric Neuro-Oncology Community.

The 17th International Symposium on Pediatric Neuro-Oncology (ISPNO) in 2016 is taking place from 12th - 15th June in the vibrant and cosmopolitan city of Liverpool. The venue for the conference is the award winning Liverpool Convention Centre set on a delightful waterfront that has achieved world heritage.

The biennial ISPNO meeting has become the pre-eminent event in the field of Pediatric Neuro-Oncology, being the only global meeting of the multi-disciplinary international community of professionals involved in the research, diagnosis, treatment and rehabilitation of infants, children and young people with Central Nervous System tumours.

### ISPNO 2016 Liverpool will feature:

- A full programme of plenary and poster sessions, keynote talks and round table discussions covering all the main aspects of CNS tumours in children and young people.
- A day dedicated to Neuro-oncological surgery - with leading international experts in Pediatric Neurosurgery.
- A full day neuro-oncology nurses meeting and a reception for nurses hosted by The Brain Tumour Charity.

- A pre-meeting Education day with state of the art lectures given by world-class clinicians and scientists.
- An open meeting of Posterior Fossa Society.
- A Family Day.

We will offer a memorable networking and social program with the Welcome Reception at the brilliantly designed waterside Museum of Liverpool, a fantastic gala dinner and optional social events at the Cavern Club – home of the Beatles – or a Latin themed evening.

## For all conference information and for a full list of our participating sponsors please visit

### www.ISPNO2016.com

We look forward to welcoming the International Pediatric Neuro-Oncology community to Liverpool.

Together we will create an incredible meeting.

With Very Best Wishes **Professor Barry Pizer**Chair of the Local
Organising Committee of
ISPNO 2016 - Liverpool.

Supported by









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#### VARIATIONS IN SPELLING

Spelling in this publication varies according to countryspecific practices and is thus variable throughout the magazine. For example, the word 'tumor' 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

THIS is our seventh annual edition of Brain Tumour magazine and with each issue that we publish, we are inspired anew by stories of courage, dedication and hope.

What stands out in this 2016/2017 edition is the diversity of people – from all walks of life, different countries, backgrounds and beliefs - who are affected by brain tumours. We have a large number of pediatric articles which highlight the fact that brain tumours also strike all ages.

In this issue, we are pleased to include excerpts from the recently-published report of the IBTA's Second World Summit of Brain Tumour Patient Advocates which was held last year in Sitges, Spain. Over 70 delegates participated from 27 countries including the leaders of the main brain tumor patient advocacy groups around the world, clinicians, nurses, representatives of industry and researchers.

As well as our usual directory of brain tumour advocacy, support, fundraising and information organisations and initiatives at the back of the magazine, we feature interviews with medical professionals and coverage of some important projects in the international brain tumour community relating to the design of clinical trials, and new treatment approaches.

We also bring you stories from two of the most challenging countries for treating brain tumour patients: Cameroon and Nigeria.

We hope you enjoy our latest selection of stories and news from the international brain tumour community.



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.





















## About the International Brain Tumour Alliance (IBTA)

The International Brain Tumour Alliance (IBTA) is a global network founded in 2005 as a dynamic worldwide community for brain tumour patient organisations, patients, caregivers and others involved in the field of neuro-oncology.



THE IBTA brings together experience and expertise from a wide range of stakeholders including patient organisations, researchers, healthcare professionals, government agencies, regulators, medical societies, key opinion leaders and others.

Our vision is a world free from the fear of brain tumours. Our mission is to advocate for the best treatments, information, support and quality of life for brain tumour patients, offering them, their families and caregivers hope – wherever they live in the world.

We work with Alliance supporters to:

- ENCOURAGE the establishment of brain tumour patient groups in countries where they don't yet exist;
- PROMOTE collaboration on programmes and projects to benefit the brain tumour community;
- HIGHLIGHT the challenges and needs of patients and caregivers;
- DISSEMINATE knowledge, information and best practice;
- HELP shape health and research policies at national and international levels;
- CELEBRATE the courage and achievements of brain tumour survivors and caregivers.

Through facilitating collaboration within the global brain tumour community, we provide a strong and collective voice for the brain tumour cause across the world.

The International Brain Tumour Alliance has contacts and distributes it's publications in 113 countries:

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Afghanistan - Albania - Algeria - Argentina - Australia
Austria Bangladesh Belarus Belgium Bhutan
Bolivia Bosnia-Herzegovina Brazil Bulgaria
Cameroon - Canada - Chile - China - Colombia - Congo
Costa Rica • Croatia • Cuba • Cyprus • Czech Republic
Denmark - Dominican Republic - Egypt - El Salvador
Eritrea - Estonia - Ethiopia - Finland - France - Georgia
Germany Ghana Greece Guatemala Hong Kong
Hungary - Iceland - India - Indonesia - Iran - Iraq
Ireland - Israel - Italy - Jamaica - Japan - Jordan
Kenya - Kyrgyzstan - Latvia - Lebanon - Libya
Lichtenstein Lithuania Luxembourg Macedonia
Malaysia - Malta - Mauritania - Mauritius - Mexico
Mongolia • Morocco • Myanmar • Namibia • Nepal
New Zealand Nigeria Norway Pakistan Panama
Paraguay Peru Philippines Poland Portugal
Qatar - Romania - Russia - Saudi Arabia - Serbia
Singapore - Slovak Republic - Slovenia - South Africa
South Korea - Spain - Sri Lanka - Sudan - Sweden
Switzerland - Syria - Taiwan - Thailand - The Netherlands
Tunisia - Turkey - Uganda - Ukraine - United Arab Emirates
United Kingdom • United States • Uruguay • Venezuela
Vietnam • Yemen • Zambia • Zimbabwe
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## Meet the IBTA team



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### An Overview of Immunotherapy for Brain Cancer

### Dr David Reardon

Associate Professor, Medicine, Harvard Medical School Clinical Director, Center for Neuro-Oncology, Medical Oncology, Dana-Farber Cancer Institute

### Professor Michael Weller Chairman, Department of Neurology, University Hospital Zurich, Zurich, Switzerland

HISTORICALLY, three pillars have served as established approaches for the treatment of cancer, including surgery, radiation therapy and chemotherapy. Based on exciting results achieved over the past few years, immunotherapy is now established as a fourth pillar of cancer therapy.

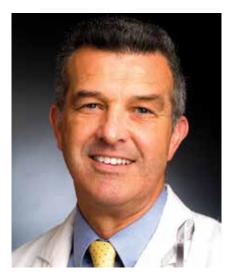
This article provides a brief introduction to immunotherapy and its application for patients with brain cancer. Its advantages and challenges are summarized and potential considerations for future development are outlined.

### What is Immunotherapy?

The primary goal of our body's natural defenses, the immune system, is to protect us against attack from anything foreign that could be harmful. Immunotherapy refers to treatments that utilize the immune system to attack cancer. Currently there are three main types of cancer immunotherapy treatment: vaccines; adoptive cell therapies; and immune checkpoint modulation.

Cancer vaccines work in a manner similar to infectious disease vaccines that protect us against harmful infections such as tetanus, polio and diphtheria. They consist of injected proteins that sensitize the immune system against an intended target. Once successfully sensitized, the immune system is actively on guard and will attack that target should it invade us. Cancer vaccines attempt to sensitize the immune system to components of cancer cells.

Most cancer vaccines are therapeutic in that they help the immune system attack existing cancers, but some cancer vaccines



**Above**: Associate Professor Dr David Reardon, United States

are also preventive, for instance, against viral proteins linked to cervical cancer.

Adoptive cell therapies are sophisticated treatments in which specific immune cells (usually T cells) are collected from the patients' blood and sensitized in the laboratory against tumor target proteins. These sensitized cells are then infused back into the patient with the goal of activating other immune cells in the body to launch a successful attack against the cancer. One type of adoptive cellular therapy called CAR (chimeric antigen receptor) T cells has been widely publicized for inducing durable remissions among leukemia patients who have exhausted all treatment options.

The third type of immunotherapy includes molecules that are designed to enhance the overall activity of the immune system and are called immune checkpoint molecules.



Above: Professor Michael Weller, Switzerland

Immune checkpoints are normally turned on whenever the immune system is activated and signal the immune system to stop reacting in order to help prevent damage to normal body organs. Unfortunately many cancers activate these protective immune checkpoints as a strategy to protect themselves by disarming the immune system especially in the immediate area where the tumor is growing.

Two important immune checkpoints which have been successfully targeted to treat cancers include CTLA-4 (cytotoxic lymphocyte antigen 4) and PD-1 (programmed death 1). Exciting results have led to approval of agents that inhibit CTLA-4 (Yervoy) or PD-1 (Opdivo and Keytruda) for a number of cancers including melanoma, lung cancer and kidney cancer while

additional approvals for other types of cancer are expected soon.

### What are the advantages of immunotherapy?

Our immune system is remarkably designed. Two of its important strengths are specificity and memory.

The immune system is highly specific and will only be sensitized against a precisely defined target. As a cancer therapeutic, such specificity is highly advantageous in that it should protect against damage to normal cells in the body. In contrast, chemotherapy and radiation therapy, while very potent against dividing cells, lack specificity and often indiscriminately affect normal as well as cancer cells.

Memory refers to the immune system's ability to remember what it has been sensitized against and retain the ability to mobilize in the future should it be exposed to that target again, even years later. Thus if memory is successfully activated, the immune system could prevent future relapse or recurrence of cancer.

Immunotherapy has additional advantages that may allow it to overcome two important hurdles that have limited the effectiveness other cancer treatments: delivery and tumor heterogeneity.

Delivery is a major issue for brain cancer because the blood supply to the brain has a protective aspect known as the blood brain barrier (BBB). Inadequate penetration of the BBB has likely been a major contributor to many drugs that have failed to improve outcome for brain cancer patients. The immune system has the ability to successfully navigate the BBB and thus the effective delivery of immunotherapies to tumors in the brain is not a major issue.

Heterogeneity refers to critical differences that define different cells in a tumor. These differences can occur geographically, meaning that cells in different areas of the tumor can be very different in many ways including their sensitivity to treatment. These differences can also occur over time in that tumor cells can change as they adapt to become resistant to treatment. Tumor geographic and temporal heterogeneity has been an insurmountable hurdle in the development of successful brain cancer treatment to date. Immunotherapy has the potential to overcome heterogeneity as long

as it can be successfully sensitized against variations that exist regionally within the tumor or are induced over time.

### What are the challenges for immunotherapy?

Although exciting progress has been made in the last few years, we are only beginning to understand and utilize the power of our body's natural defenses against cancer. Additional laboratory and clinical research is desperately needed. Even among tumors where immunotherapies have been approved, only a minority of patients achieve durable benefit.

Why do some patients respond and others do not? Similarly why do some types of cancer respond better to immunotherapy than others?

The answers to these questions likely involve two factors: optimization and resistance.

There are a host of variables that must be optimized for successful sensitization of the immune system. For example, several variables can impact the effectiveness of a cancer vaccine including: when, how and where to administer it; which patients are best candidates; does the amount of resected tumor matter; and what is the impact of other therapies such as radiation or chemotherapy.

Another critical challenge for immunotherapies are mechanisms of resistance that tumors can use to evade attack by the immune system. Many cancers, and especially brain cancers, are remarkably adaptive in their ability to develop resistance capabilities that allow them to flourish despite our best attempts at treatment. Ongoing research has identified a wide array of protective resistance mechanisms cancers can exploit to protect themselves from immunotherapies as well.

The reason for the disappointing negative results recently reported for rindopepimut, a glioblastoma vaccine against EGFRVIII, in the large phase 3 ACT IV study, is not clear, but it is likely that tumor resistance mechanisms designed to suppress immune responses, probably were a major contributing factor. Due to the existence of resistance mechanisms, combination treatments that bring together complementary approaches will likely be required.

There are additional practical challenges

for immunotherapy that are particularly relevant for brain cancer patients.

First, immunotherapies typically stimulate inflammation as an inevitable part of the immune system's attack against cancer. Inflammation can cause brain swelling which can temporarily worsen neurologic deficits. Second, steroids such as dexamethasone which are commonly used to decrease brain swelling can cripple the ability of immune cells to attack cancer. Third, inflammation caused by immunotherapies can make accurate interpretation of MRI changes difficult because such reactions can mimic tumor growth. Expert panels are developing guidance for the neuro-oncology community to help deal with these challenges.

#### **Future Considerations**

Thanks to much intensive research, a variety of immunotherapies have achieved exciting success across a spectrum of cancers recently. Hopefully, these successes are just the beginning. Nonetheless, in order to realize the potential benefit of immunotherapy for brain cancer patients, much work remains to maximize the powerful advantages of the immune system while overcoming challenges including resistance mechanisms exploited by cancer.

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

For more information, visit www.theibta.org

### **OUR COVER STORY...**

## So much has been taken from me - but dance remains!

Anna Mott

Marietta, Georgia, United States

When 18-year-old Anna Mott was diagnosed with a rare pineoblastoma brain tumor, the ballerina thought she had lost everything. The tumor left Anna blind and unable to walk. But thanks to her incredible determination, and the love and support of her family, Anna is now dancing again, joyfully and courageously. Here, Anna shares her inspirational story of perseverance with our readers.

IN 2011 I was a typical teenage girl. I was working my way through high school while attending ballet and dance classes six days a week at my pre-professional ballet school. I had no idea that my world was soon to turn upside down, plus some.

By the spring of that year, I had acquired an intense, unyielding pain in my lower back. My parents took me to doctors and specialists and it was decided I had a stress fracture from dance. Physical therapy was prescribed and over the course of the spring and summer, it got better, good enough for me to fly out to Kansas City for a summer dance program.

I returned home and excitedly began

**Below**: Just before she was diagnosed with a pineoblastoma, but already suffering substantial symptoms from it, Anna Mott danced the role of Dew Drop Fairy in *The Nutcracker* 



Nutcracker rehearsals for the Christmas season. I had been cast in my dream role of Dew Drop Fairy so I was especially excited. To my surprise and utter disappointment, the back pain returned with a vengeance as rehearsals picked up that fall, and I was in intense pain. My parents wanted me to give up the part and seek rest, but I just had to do this part. I somehow knew it would be the last time I would get the chance, and it meant everything to me. I had worked for years

When the last *Nutcracker* show ended, I was in so much pain in my back and legs, I had to be carried to the car. My mom had already lined up an appointment with a couple of specialists for the week and I was eager to go, as I now had no feeling on my left side from my knee down.

to reach the level of

dance to perform this.

I saw many pediatricians and specialists throughout the spring and summer of 2012, yet none could help me find relief. I began having intense headaches and other symptoms as well. By August 29, my parents had enough and took me to the local hospital emergency room. Within an hour, they had done a CT scan and found a mass in my brain. I was transported right





**Above**: Anna, pre-diagnosis. Photo by Richard Calmes, www.richardcalmes.com

away to Scottish Rite Hospital in Atlanta, Georgia [US].

Things happened at lightning speed after I arrived. A drain was inserted to relieve all the pressure on my brain, my mass was biopsied and then I had two resection surgeries that got out 95% of my tumor. The official diagnosis was pineoblastoma, a rather rare, aggressive brain tumor.

I can't remember much from this time, but my parents and family tell me I was really brave and that my chief concern was making sure that my siblings were okay and that through all this, I would glorify God and hopefully help others. My mom said I never broke down or even cried. All I wanted was to be as strong as I could and let God use my situation.

From arrival at the hospital until my first discharge, I was there a full 12 weeks. Besides my two surgeries, which were very invasive, I battled a bacterial infection in my brain and spine, I also endured 33 full brain and spine radiations with simultaneous chemo treatments, I lost



**Above**: Anna is supported throughout her brain tumor journey by her very close-knit family including two brothers and two sisters (who are also ballerinas). Photo by Helmuth Photography www.helmuthphotography.com

and regained use of my left side, I had to re-learn to walk, and so much more, including the fact that my optic nerves were damaged and I was now blind.

I'm thankful that my mom was with me every moment, and that my dad brought my two sisters and two brothers nearly every day to visit me. The hospital was great about letting one of them stay over to be with me. That encouraged me and helped so much. They brought a bit of "normal".

I had tons of cognitive challenges, as the surgeries were so invasive. My sisters, who are also ballerinas, would play music from ballets I had danced, and quiz me on them. They also showed one of my therapists "ballet arm" positions so that she could help me learn to use my arms again. My brother would come with me into the therapy gym and cheer me on, encouraging me that I could do it. My baby brother would make me laugh. My siblings were all such good medicine for me while I was in the hospital.

As I transitioned home, I was walking

again, but blind and very weak, and still had six months of chemo ahead. I soon ran out of benefit payments for therapy, but my family and friends were constantly finding ways for me to keep moving.

Some friends from my former ballet studio made me a portable ballet barre so my sisters gave me a barre class at home.

My friend, Keiko Guest, who is an acclaimed local dance photographer, was having a gallery showing in April 2013 of her new collection. She decided to shoot me as part of the collection and then had the idea for me to dance at her opening night. From the moment I got sick, Keiko had been the one person who said I would dance again and she found a way for me to do it! She and my dear ballet mistress who had taught me since I was a little girl of five, Lisa Sheppard Robson, choreographed a dance and coached me through it. This was the first time I had danced since my *Nutcracker* in 2011.

After this, Keiko introduced me to a dance and gymnastics teacher, Cindy Bickman, who works with special needs

dancers. She has given me many opportunities to dance again. It's amazing that I had lost so much memory, so much cognitive and physical ability, and even my sight, but ballet was still in my brain and my muscle memory. When I thought the problem was my back and I had to stop dancing from the pain, I thought dance had been taken from me. Now, although so much has been taken from me, dance is the thing that remains. Through ballet, I have regained much. It has given a life back to me.

I'm almost four years out from diagnosis and I'm happy to still be "NED" ["no evidence for disease"]. I'm not exactly sure what my future holds. I hope to continue to recover physically and mentally, and to take each day one at a time, being thankful for each as a special gift. I believe dance will always be part of my life. It has generously given so much to me. I hope to use it to give back. My goal is to continue to rise to each challenge I am presented with and to glorify God.

Right: Anna (center) returns triumphant to ballet after her treatment for a brain tumor



### 4th Brain Tumour Awareness Day (Argentina)

THE fourth annual Argentina 'Brain Tumour Awareness Day' took place on 27 October 2015 at the Argentine Medical Association, Buenos Aires. Results from a survey conducted throughout 2015 that examined "The accessibility to diagnostic methods and treatment of brain tumours in Argentina" were presented. This represents the first such survey of brain tumours ever undertaken in Argentina.

The event was attended by representatives from a broad range of specialties, including neurosurgery, neuro-oncology, pathology, radiation therapy, palliative care, psychooncology and public health. It is hoped that this meeting will be the initial step towards gaining academic support for quality



Above: Participants in the fourth annual Brain Tumour Awareness Day in Argentina

management improvement in brain tumour care, leading to equitable neurosurgery practice in Argentina. The presented study is to be published in in the Revista Argentina de Cancerología (Argentina Journal of Cancer); the Revista Argentina de Neurocirugía (Argentina Journal of Neurosurgery) and on The Argentina Cancer Society website. The meeting was supported by The Argentine Association of Neurosurgery, the Section of Neuro-oncology of the Latin-American Federation of Neurosurgical Societies.

### GBM AGILE - A Story of Convergence, Commitment, Collaboration and Compassion

Anna D. Barker, PhD, Director, National Biomarker Development Alliance; Executive Committee Chair, GBM AGILE Trial; Co-Director, Complex Adaptive Systems, Professor, School of Life Sciences, Arizona State University United States



### **GBM** is Unacceptable

TENS of thousands of people are diagnosed with glioblastoma multiforme (GBM) on a global basis each year. With a median survival of 14 months and only 5% of patients living five years or longer, GBM is a grim diagnosis. Despite hundreds of GBM clinical trials, testing hundreds of agents, there have only been four approved GBM treatments, and the dismal prognosis for GBM patients has not changed in decades.

In addition, despite significant progress in molecularly characterizing GBM through projects such as the Cancer Genome Atlas (TCGA), the stark reality for GBM patients is that there are no treatment-associated biomarkers and no viable therapies with a



Above: Dr. Anna D. Barker

long-term, positive treatment effect. While a number of cancer types are celebrating the dawn of precision medicine, the lack of GBM biomarkers to guide therapy (and effective treatments) means that GBM patients could be left behind – a future that is unacceptable.

### **Coalition of the Willing**

Disillusioned with the status quo for GBM patients, Dr. Web Cavenee (Director of Strategic Alliances at the Ludwig Institute, USA), Dr. Al Yung (Director of the Brain Tumor Center at MD Anderson Cancer Center. USA), and I joined forces to organize a series of think tanks to determine what we know and don't know about GBM - and, more importantly, to create new research models and projects that could really make a difference for patients. These first think tanks convened about 40 leaders with varied backgrounds, who had reputations for being innovators and were unified in their commitment to provide a new source of hope to GBM patients and their families.

The meetings identified a number of "big ideas", including how we might identify

Below: United States Vice President Joe Biden, who lost his son Beau Biden to GBM in May 2015, joins GBM AGILE leaders at a reception following the National Press Club announcement.



effective therapies for GBM and overcome barriers to progress to date. Although traditional randomized controlled trials are considered the gold standard for drug testing, they have significant limitations especially for rare diseases. Traditional trials require hundreds of patients to achieve statistical significance, (at a cost of over a billion dollars per agent) and take years to complete before determining if drug A works better than drug B. If the drug succeeds, we often learn little as to why, and if it fails, we often learn nothing. In all of these traditional trials, there is little if any learning from single patients and these trials cannot change to accommodate new knowledge.

Taken together, this bleak picture drove a decision from the think tank participants to form a global coalition that would plan, design, and implement the first adaptive clinical trial for GBM. And while everyone embraced this "big idea," we were all acutely aware that such an unprecedented trial would challenge dogma and require the integration of what we know about GBM both scientifically and clinically from around the globe. GBM AGILE was born – and became in every sense a "coalition of the willing."

### "Crowdsourcing" Knowledge

Given the historical lack of success for GBM clinical trials, we knew that identifying effective therapies for GBM would require a "learning system" - a system that is more efficient, faster, and patient centric than traditional trials. Thus began GBM AGILE's quest to "crowdsource" knowledge from leaders in GBM research, innovative clinical trials designers, biomarker experts, clinicians, basic researchers, and patient advocates. Fortunately, several members of the group working on GBM AGILE were part of the team that designed and implemented the I-SPY 2 trial in breast cancer, one of the most transformative clinical trials performed to date. Although there are significant differences between a rare cancer like GBM with essentially no successful therapies or biomarkers and breast cancer, lessons learned from this innovative trial have been helpful to the AGILE Global team. It is our hope that other rare cancers can similarly benefit from GBM AGILE.

The concept of combining our knowledge and expertise to create the first global adaptive trial for GBM quickly



Above: GBM AGILE announcement November 12, 2015 at the National Press Club in Washington, DC

became something of a "movement," and in a few months, our original group of 40 visionaries expanded to include over 150 leading neurosurgeons, neuro-oncologists, neurobiologists, imagers, and patient advocates from the US, China, European Union, and Australia. United by a simple goal of bringing better treatments to GBM patients, everyone stepped out of their silos, left their egos, and paid their own way to work with colleagues from around the globe to undertake the planning and development of this remarkable project we named GBM AGILE. AGILE stands for Adaptive Global Innovative Learning Environment - truly a descriptive acronym. Crowdsourcing the knowledge we need for GBM AGILE will continue throughout the trial, ensuring that learning from both inside and outside of the project is incorporated as it evolves over time.

#### **Every Patient Counts**

GBM AGILE differs from traditional clinical trials in that it will employ a Bayesian, adaptively randomized trial framework that enables testing many different hypotheses (therapeutic arms) and associated biomarkers simultaneously. Bayesian refers to a statistical model that builds on prior information to determine probability of an outcome. GBM AGILE will be a standing phase II trial, conducted under an FDA master protocol, which provides flexibility to add and drop drugs through mutually-agreed processes. The master protocol reduces time and increases the efficiency of all aspects of the trial. GBM AGILE will include both newly

diagnosed and recurrent patients who do not carry the IDH1 mutation.

Several classes of biomarkers will be included (and further investigated) in the trial, but two categories, stratification biomarkers and enrichment biomarkers, are seminal to the design and conduct of the trial. The former will allow initial assignment to subgroups that require different treatment at baseline; and the latter will be used to predict response to specific agent(s). These two classes of biomarkers may ultimately combine to become a biomarker signature for a specific arm of the trial. The primary endpoint for GBM AGILE is overall survival, but a longitudinal model is also being developed to inform and learn what aspects of the disease may predict for survival.

Eligible primary and recurrent GBM patients will enter the trial and primary GBM patients will be stratified based on the presence or absence of a critical genetic marker involved in the repair of DNA (DNA methylation status or MGMT). Patients with methylated MGMT have a longer median survival than un-methylated patients, so MGMT status serves as an effective stratification biomarker for primary GBM patients. Following stratification, patients will be randomized to receive differential standards of care (depending on MGMT status) and further randomized based on enrichment biomarkers that are associated with specific potential therapies. Interestingly, by including both primary and recurrent GBM patients, we will learn if specific agents might work in different GBM settings.

As the study proceeds, the GBM AGILE trial (learning system) will learn from every patient, and similar patients (as determined by subtypes and enrichment biomarkers) will have a higher probability of being assigned to a successful agent. Conversely, patients will no longer be randomized to agents that perform poorly in a specific subtype. As the trial proceeds, arms will come and go – and successful agents will "graduate" with their signatures, fully ready to enter a phase III trial. This means that a pharmaceutical company can pursue a phase 3 trial using a relatively small number of patients, patient and financial resources, and, of course, time.

### Adaptive Global Innovative Learning Environment (AGILE)

The National Biomarker Development Alliance (NBDA), a nonprofit organization founded by Arizona State University and focused on the development of biomarkers for precision medicine, hosts the planning and, along with foundations and other donors, provides support for the 12 committees tasked with making AGILE a reality.

The master protocol and data system will be centralized to support all facets of AGILE. AGILE will initially be implemented in the US and Australia, then followed by China and Europe. There are hurdles yet to clear, but we have an ambitious and aggressive timeline to begin enrolling patients in the autumn of 2016.

Although our efforts thus far have been fueled by volunteers and patient advocacy organizations, fundraising efforts are underway to raise much needed capital to implement the AGILE trial. We seek philanthropists, research organizations, and individuals who care about improving outcomes for GBM – and for all cancer patients and other rare diseases.

For more information about the GBM AGILE Trial or to learn how to get involved, please visit www. nbdabiomarkers.org/gbm-agile or contact kristyn.pineda@asu.edu

The 2016 International Brain Tumour Awareness Week is from 22nd to 29th October.

### Snowdon Trek (United Kingdom)





ON Sunday 21 June, 2015 a party of twenty walkers, plus three large dogs, set off on the 'easy' Llanberis route of Snowdon, the highest mountain in Wales, UK. IBTA's Kiki Connor walked alongside representatives from three brain tumour charities. With her on the climb were: Heather Othick (aka "Ellie's Mum" from Ellie's Fund Brain Tumour Trust), Rachel Finlay (Charity Manager for BT Research & Support Across Yorkshire - not pictured), Paula Holmes (The Katy Holmes Trust), IBTA supporter

Marilyn Rankin, Zoe Boult and Kiki's husband Andy.

Ignoring the train that was happily chuntering up and down the mountain all day, the trek turned out to be long but not too difficult. Conditions were cold, cloudy and windy all the way to the top but the climbers were rewarded with amazing views as the cloud cover lifted. The mileage achieved on the mountain walk was donated to the IBTA's Walk Around the World for Brain Tumours.

### 3rd Brain Tumour Alliance Australia Summit (Australia)



ON 22 October 2015 for International Brain Tumour Awareness Week, Brain Tumour Alliance Australia and Cancer Council Queensland (CCQ), with support from the Cure Brain Cancer Foundation, hosted the 3rd Brain Tumour Alliance Australia Summit, a lunch, and special educational forum at the CCQ Brisbane offices, Queensland.

Among the speakers was the internationally-recognised Professor Martin van den Bent. Michelle Stewart from the Cure Brain Cancer Foundation presented news on clinical trials. Although unable to attend in person, Australia's Federal Health Minister, Sussan Ley, gave a welcome message for the Summit.

For more information on Brain Tumour Alliance Australia visit https:// www.btaa.org.au

# Petition leads to milestone Westminster debate in the UK on research funding for brain tumours

WHEN UK MPs met at Westminster to debate the issue of research funding for brain tumours it was the culmination of more than 15 years of campaigning.

The event was a milestone because it came as the direct result of patients and their families, activists, campaigners and lobbyists, joining together with the national charity Brain Tumour Research to highlight the lack of progress in improving outcomes for patients affected by this devastating disease.

The petition was started by journalist Maria Lester who lost her brother Stephen Realf to a brain tumour at the age of 26. It was launched in August 2016 as part of a moving account of the family's loss which was published in the Mail on Sunday's YOU magazine to mark the first anniversary of Stephen's death.

As the petition gained momentum, the UK Parliament's House of Commons' Petitions Committee launched its firstever inquiry which saw Stephen's family among those called to give evidence.

The report which followed found that research funding in the United Kingdom was inadequate and that the Department of Health had not "grasped the seriousness of the issue." Health officials were criticised for "failing brain tumour patients and their families for decades" and the report concluded that "patients with brain tumours are failed at every stage – from diagnosis and treatment to research funding."

With a final tally of over 120,000 signatures, the petition far exceeded the 100,000 names needed to secure the debate a month after the report, which received worldwide media coverage, was published.

Sue Farrington Smith, Chief Executive of Brain Tumour Research, who lost her



**Above**: In the heart of Westminster, London - Stephen Realf's sister Maria Lester (centre) with Stephen's father Peter Realf and Sue Farrington Smith of Brain Tumour Research

niece to a brain tumour shortly before her eighth birthday, said: "Unlike many other cancers, the incidence of brain tumours is increasing and it is appalling that to date so little has been allocated to research. Many thousands of families continue to be shocked by the lack of treatments available and clinicians continue to deliver a poor prognosis, causing untold distress to patients and their loved ones."

Brain Tumour Research funds four dedicated UK brain tumour research Centres of Excellence and is striving to establish three more. It is challenging the British Government and larger cancer charities to increase the national investment in brain tumour research to £30-£35 million each year, the same level of investment other cancers, such as breast and leukaemia, receive.

Sue Farrington Smith said: "The scheduling of this debate is hugely

significant and feels like the culmination of all of our efforts over the last fifteen years since we lost my beloved niece Alison Phelan to a brain tumour.

"I want to thank Maria Lester and her family and also acknowledge the vast army of activists across the UK who were able to ensure the petition reached its target. So many people also went on to work with us to lobby their MPs to attend the debate as we continue our campaign to increase the level of funding for research into brain tumours and, ultimately, find a cure. I think this is a great example of democracy in action and demonstrates what can be achieved when people collaborate and work towards a common goal."

Stephen Realf was training to be a pilot with the Royal Air Force. He died six years after being diagnosed with an astrocytoma. Stephen underwent surgery

and treatment but, in Maria's words, "while these measures brought him precious extra time, it quickly became clear that his condition was incurable."

Commenting on the success of the petition, Maria Lester said: "For me, this campaign began with one boy. One boy with his whole future shining brightly ahead of him, before he found out at the age of 19 that he had an incurable brain tumour. Stephen Realf was my brother, and it broke my heart to watch his health decline and know that there was nothing that could be done to save him. When the first anniversary of his death came around, I wanted to do something that didn't dwell on the tragedy of the situation, but which reflected his incredible positivity of spirit. The idea of a petition took hold, and after six short months we had gone from one boy to over 120,000 signatures and a Parliamentary debate.

"I know this doesn't mean that we're home and dry. The change we seek is not going to come overnight. But there are 120,000 of us now, all shouting with one voice, and I hope that the Government is listening. In the meantime, I'd like to personally thank Brain Tumour Research and every single person who has supported this petition. Together we will find a cure."



**Above**: Pilot Officer Steve 'Realfy' Realf took his first solo flight on 16th November 2007. Photo courtesy of the UK Ministry of Defence

### Brain Tumours - UK Statistics

- Brain tumours kill more children and adults under the age of 40 than any other cancer.
- Just 1% of the UK national spend on cancer research has been allocated to this devastating disease.
- In the UK, 16,000 people each year are diagnosed with a brain tumour.
- Less than 20% of those diagnosed with a brain tumour survive beyond five years compared with an average of 50% across all cancers.
- One in 50 of all people who die under the age of 60 die from a brain tumour.
- 71% of those who die of a brain tumour are under the age of 75 (compared to 47% for all cancers).
- Unlike most other cancers, incidence and deaths from brain tumours are increasing.

Statistics from Brain Tumour Research – www.braintumourresearch.org

## UK Government acknowledges more must be done for brain tumour patients

THE UK Government has formally acknowledged that more needs to be done for brain tumour patients and their families.

Health Minister George Freeman MP announced a package of measures at a Westminster Hall debate on Monday 18th April which was prompted by an e-petition launched by the family of Stephen Realf, lost to a brain tumour at the age of 26, and backed by the charity Brain Tumour Research.

### The UK Government will:

- Set up a "Task and Finish" working group at the Department of Health looking at areas highlighted by the Petitions Committee report.
- Request the National Institute for Health Research (NIHR) produces a national register within a year to examine how public funds are spent on brain tumour research.

 Seek to improve levels of earlier diagnosis and include brain cancer in the Genomics England programme.

Mr Freeman formally accepted the Petitions Committee report which found that patients and their families had been "failed for decades." He praised the "extraordinary campaigning" of so many individuals and charities who were: "lifting a torch and joining a magnificent history of people who, through their suffering... drive campaigns and raise awareness, leading to increased funding."

Shadow Health Secretary Andrew Gwynne MP thanked Brain Tumour Research for its support of the petition and in helping MPs better understand issues relating to the disease. He added: "The charity Brain Tumour Research which champions research across

the country, has estimated that between £30 million and £35 million a year over ten years is needed to make a significant impact on brain tumour treatment."

Sue Farrington Smith, Chief Executive of Brain Tumour Research, said: "I am immensely proud that, with the support of thousands of patients, families and activists, the woeful underfunding of this dreadful disease has finally been acknowledged. Our voices have been heard and the work of the past 15 years has not been in vain.

"So many of the key issues highlighted in our Invest In a Cure manifesto have been addressed and we will continue to apply pressure to ensure genuine progress is made. We have reached an important milestone on our journey and we will continue with renewed hope and determination."

## THE COUNCESOOK CHREFOR CINGERY

### Picturing life with an oligodendroglioma brain tumor

### Adam Bessie, Professor of English Berkeley, California, United States

ON my 29th birthday, I was in the stroke ward of a rehabilitation center reading *The Incredible Hulk*, watching him jump, sprint, run and smash – pretty much everything I couldn't do, and feared I'd never do again.

Days before, I awoke from a successful resection of an oligodendroglioma (grade II) to find my right side essentially browned-out, as if my electric grid had been severed – there was no more power. My right foot, leg, trunk, arm and hand had been disconnected, and in the place of power, control and muscle, I found an alien entity, a weak and numb bulk of flesh. By stark contrast, my left side was completely normal, as was my mind, my memory, my speech; it was just that half of my body had been powered down.

I'd gone through a reverse-Hulk – from powerful to powerless. I had been a responsible, physically-capable, independent adult: just three days before the surgery, I interviewed with the president of a college for an English professorship, I was engaged, and planning a wedding. I ran daily – indeed, in university, I had run on the cross country team. But after the surgery, I couldn't run – that seemed impossible. I couldn't walk. I couldn't go to the bathroom by myself. I couldn't hold a pen well enough to write my own name. I was in a man's body, but utterly dependent, thrown back to a child-like state.

However, I could read – and I was compelled to return to *The Incredible Hulk*, which I hadn't even looked at since I was a kid. The Hulk – like all superheroes – uses his great power to defend the small, the weak, the vulnerable – that's why kids love superhero comics, to discover the power that they lack in themselves. And indeed, that's why, in my weakest moment, I returned to The Hulk. I needed desperately to find a



Above: English professor Adam Bessie hiking with his son Sol

source of power – it was a matter of survival.

I didn't want to be superhuman – just human would do.

But I was plagued by doubt. Could I return to my life? Would I be able to teach again? Would I be able to walk down the aisle to get married? Or would all my dreams, my hopes for the future, be as fantastical as a superhero comic book?

Was my life over at 29?

Indeed, it was over – after the diagnosis, after the surgery, after the rehab center, my life as I knew it ended. Life after has been more unreal than *The Incredible Hulk* I read in my wheelchair – which is why I knew I wanted to tell my story in comics.

Outwardly, to the untrained eye, my story

followed the typical heroic brain tumour narrative: I overcame barriers, even smashed them as The Hulk might. I learned to walk; I walked down the aisle; I hiked about Mt. Waialeale in Kauai on my honeymoon; I got the tenure track English job – and just recently, was a member of the panel for the tenure track English committee, to hire new full-time professors. This was the same panel, seven years prior, which I had stood before, my future completely and utterly uncertain.

The most fantastic adventure, though, has been fatherhood: we have a son, Sol, a healthy, strong, hilarious four-year old – who himself loves *The Incredible Hulk*, which we can read together. Every Saturday morning,

I run up a hill with Sol in the jogging stroller, talking, laughing, living. In most all ways, my life now is fuller than I could have ever dreamed when I was rolling about in the rehab center.

This tale would make for a great comic, but like *The Incredible Hulk*, it would be a sort of simple superhero fantasy: the reality has been far more complex. Every step forward has been an incredible fight, one often not visible, even to my closest friends, and certainly not my colleagues.

Over these same last seven years, my right side has regained power – it's functional, but still, weak, uncoordinated, and still slightly alien. During this time, I've endured two year-long rounds of Temodar, and one round of radiation, all while working full-time. And of course, all along the way, are the constant scans, every three months, with the looming question: will I lose it all now? Is this it?

Is my life over at 35?

This tension – between the outward success and the inward struggle – is my inspiration for making non-fiction comics, which have been published in many national outlets,



Above: Adam's comics aren't comic. (Reprinted with kind permission From "A Scanner Constantly." 2015. Adam Bessie and Josh Neufeld, as first published in Pacific Standard Online @ www.PSmag.com)

including the Boston Globe, the Los Angeles Times, and the Pacific Standard. My comics aren't comic; they are pictorial essays for adults, ones that attempt to render visible the invisible struggles of living with brain cancer.

Collaborating with artists, I strive to illuminate my struggles and successes as realistically as possible: I explore my initial diagnosis, the challenge of living under constant scanning, my experiment with medical marijuana to deal with chemo, and what it's like, overall, to live with an "uncool cancer." My goal is to show those

unseen struggles to the world in all their terror, beauty and complexity.

But most of all, my goal is to reveal my humanity, to show that folks with cancer are more than a disease, more than a ribbon or a wristband, but most of all, people - regular, real people.

This is my comic book cure for cancer. -

To see more of Adam's comics, please visit adambessie.com



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## I know where the lightning strikes

### Catherine Klopper Johannesburg, South Africa

18 DECEMBER 2015. Where were you the day the world stopped?

I was sitting in a doctor's office. A pediatrician's office to be precise. With my husband, Ralph, and our little boy Henry, fast asleep on Ralph's shoulder. We'd been there a dozen times before. It was familiar, comfortable. Ordinary.

The colourful fish mobile above the examination bed. The slightly out-of-proportion cartoon characters stuck to the window. Had the Santa always been there or was that new? The soft gurgle of the fish tank behind us.

Just another ordinary day in the doctor's office.

It was hot, the whole summer had been hot so far. But we'd been in the hospital for a couple of hours, and despite the irritation of waiting for the sedation and then waiting for the scan and waiting for the report and waiting for the doctor, we were enjoying the air conditioning. But I'm getting ahead of myself... let's start in November.

Ralph spent several hours setting up



Above: Catherine and Henry

the trampoline. It was the 'main' Christmas present for Henry. And the effort was worthwhile - Henry was loving it, doing his somersaults and running around the perimeter, around Ralph or me.

A day or two later, or maybe it was the same day, was the first time he touched the back of his head and complained of the pain.

Ralph wanted to know if he was touching his head, or his neck. It was his head. No, definitely his head, not his neck. Still, most likely one of those somersaults hurt his little neck and this was what was causing the pain. Bring on the Calpol and he'll be fine.

It's two weeks later and the headaches are getting worse. We don't play on the trampoline anymore. We don't play like we used to anymore. Every time Henry laughs his infectious, raucous laugh, the stabbing head pain comes back and stops him. Same when he coughs. It's time to see the doctor.

So we're back in that room with the fish in the tank and on the mobile, and the stickers on the window, and the familiar Nemo toy on the desk. The doctor is irritable, it seems to us. He's rushed and

impatient, and Henry is screaming and fighting and the sweat starts pouring down his head and face. The doctor is doing so many tests push his head down, push it back, scratch his feet, test his reflexes, light in the eyes, the ears, the nose, the stick down the throat.

All the time Henry is screaming and crying and doesn't understand why this normally nice doctor isn't nice today. And he doesn't understand why Ralph and I are holding him and letting the doctor do this to him. "He hurt me". I think my heart breaks at these words, but as yet I have no idea what heartbreak means.

Eventually it stops. There's nothing wrong. Henry passed all the tests. Go home and carry on with Calpol.

So we do.

A week later we're back in that damn room with the damn fish and the damn Nemo on the desk and we're telling the doctor that something is wrong. The pain is getting worse. The medication isn't working. It's killing Henry's laugh, and his laugh is him, it's always been what he's about.

We know what the doctor is going to say, because it's what we were going to insist on. MRI tomorrow. Time to rule out anything seriously wrong, and we all grin weakly because we know deep down we're being paranoid and this is an expense and it's just going to show nothing's wrong. The doctor gives us permission to be paranoid, and we smile. Then we talk about what our options are when the MRI shows nothing's wrong, like we know it will, and the doctor mentions physiotherapists and chiropractors and psychological issues.

I remember feeling nervous about chiropractors. Well, I thought I was nervous. I still had no idea.

It's the morning of the MRI. We need to be at the hospital at 7am, so that Henry can have his sedatives before he goes in for the scan. It's already busy, and our little monkey is full of energy and cuteness. Someone







comes along and gives us two syringes and tells us he needs to swallow the medicine, although they taste really bad. Henry already doesn't like taking medicine, so this is going to be fun.

After negotiating for playtime on Ralph's phone, he has the first one, gagging and screeching that it's yucky. And it's the second one that's really bad. Somehow we get them in. Most of them.

The assistant tells us that he will start to lose balance and become disorientated, and that he's going to fight the sedative. After about 15 minutes he starts swaying, still trying to run around and be active. We grab hold of him but he's having none of it, and the tension is rising. We're sitting in the reception, which is full of people now, and Henry is kicking and hitting and screeching and our nerves are singed at the tips and very raw.

Eventually someone calls us through and says we should put him on a hospital bed and cover him with a blanket. He's still very disorientated but not yet asleep, and he's kicking the blanket off as we try to calm him and those nerves are on fire now.

Eventually, he seems to be asleep, and it's time to go through to the MRI room. He looks so tiny, so fragile and little and alone, and my eyes start to feel thick and liquid. There's a big window, and the assistant brings me a chair so that I can sit and wait. And the moment I see him go into that damn machine the thick, liquid eyes just crack like a raw egg and spill their contents all over and I don't care.

The super-cheerful assistant comes out and says something half amusing, half comforting, and again it's that weak grin because she too knows that it's nothing and that we're being paranoid. And I know she's right, of course she's right, but he just looks so fragile and I feel so far away from him, the tears won't stop.

It's ten minutes later and they stop and go back into the room - two radiographers this time. Ralph is sitting next to his boy, and I stand up and stare through the window because I can hardly bear not being in that room with Henry, and I sneak a look at the screens that the radiographer was looking at during the scan. I see his little head - the insides of his little head - and I wonder if all angels look like that on the inside. But the scans mean nothing to me.

In the room Henry is struggling and there's an IV and I can't tell what they're doing but I can hear him moaning and fighting and Ralph and the radiographers are trying to keep him still. The nerves are all burning outright now, and it's all I can do to not run in there and rip them off my child.

More scans, more screen watching, and eventually it's over, and I run into the room to see Henry and he's fast asleep, peaceful. We bring him out and he's back on the hospital bed and the assistant comes along and connects a heart monitor to his tiny little finger and tells us we need to wait.

Eventually the cheerful assistant says we can go. Henry is restless but still out, and we really just want to get home. But we go along to the doctor. Ralph says we should just go home and I say we should just give him a short while and if he takes too long we'll leave.

Irritated again.

We walk into the doctor's reception and it's packed, and we're both thinking that

there's not a chance in hell we're staying waiting for all these people.

But after just a few minutes the people with the doctor come out, and they don't call anyone else in. A few minutes later the doctor comes out and he ushers us in. And we're relieved and happy that it won't be much longer and we can start our weekend. Henry is passed out on Ralph's shoulder as we sit down in the chairs in the room with the fish and the window stickers.

The doctor isn't smiling. We are, weakly. We just want to know it's nothing and go.

He looks at us and says: "I'm afraid it's not good news - it's actually very very bad news."

The tears come immediately and easily and he starts saying things like "mass" and "worst" and "can't do surgery" and "hate giving this news, it happens once a year" and who knows what else because my ears are ringing and I'm sobbing and I don't understand. And he keeps saying sorry. So sorry.

Something about an appointment... and blood tests... and collecting the MRI CD... and then we're leaving the room with a piece of paper in our hands and Ralph walks right out with a sleeping Henry, his face contorted in pain and wet from the tears.

I'm at the reception, trying to pay, sobbing and red and wet-faced, and I think it's probably deathly quiet in the reception, but I don't know, and the receptionist is saying not to worry we can do it another time and I don't thank her, I just walk out.

And I walk into Ralph holding our son and we hold each other and just sob, not caring where we are or who is around us or what is happening. And Ralph says "We can't lose him" and we sob even louder.

And eventually we make our way to the blood tests and clutch each other in pain and shock and fear as the tears go on, and somehow I collect the MRI CD and I guess we make it back to the car, because somehow we end up at home. And it's all just a blur that I don't remember, except for the fear. The type of fear that clutches at every part of your body and mind and soul and squeezes so tight it's hard to breathe. A fear that from that point on just Won't. Let. Go. Ever.

And I realise that I now know where the lightning strikes. It struck our beautiful, precious, kind, generous, sweet little boy.

I don't know when, or why. But I know where the lightning strikes.

Photographs: Luke Tannous Photography

## Brain tumours in Cameroon: a journey of hope

Irene Azong-wara, Founder Jacob's Hope Foundation, Cameroon, Africa

HOPE is a strong word to use when you have little access to a good health care system and limited finances. Yet there is hope.

We in Cameroon come from a society where we fear going to the hospital. When we get headaches and pains we go to the local chemist and buy whatever they have for pain no matter what kind of pain. When that does not work we go to the ritualistic healer who considers the illness as some sort of witchcraft. Later we turn to the church and God to cast out the demons in us. Before we get to the hospital sometimes it is already too late for doctors to help.

The diseases we see in African hospitals are horrible. The challenges faced by the patients, doctors, nurses and caregivers are unbelievable. Yet we still have some survivors. This gives us hope as we make the cancer journey.

### My family's brain tumour story

It all began in March 2015.

My father is considered one of the strongest men in our community. He had the largest farmlands and many children under his care. Yet, he was hunted down by cancer. He had never been sick all his life. But he had a cold that he had been struggling with for over three months and was treating it with the regular medication he got from the pharmacy.

As strong as he is, he carried on with his daily activities making sure he prepared his farmland for the next planting season. His face became swollen; he had heavy discharge from his nose; he had headaches and sweated profusely around his head. With all this he decided to go to the best mission hospital in his area. There he was treated for stenosis for over six months.



Above: Founder of Jacob's Hope Foundation, Irene Azong-wara from Cameroon

He didn't get better. The man who was considered so strong was apparently almost dying of a cold!

"This is definitely some form of witchcraft!" cried my grandmother.

"We have had other people like him who complained of just a headache and died the next morning," said another person.

"He is dying, the hospital cannot find anything!" others cried.

My father had sold his corn from the last harvest to the government and had been waiting for over a year for the money. He barely had money to pay for his last bills. This money has still not been paid as I write. Poverty is a very serious issue in Africa. Many people never make it to the hospital because they do not have the financial means to pay for treatment.

### A diagnosis at last, but a shocking one

My father's health did not improve. Reality now set in. We had no money to do

the CT scan, the X-ray and pay for the consultations. My mother went to the government officials to find out when they would be paid their money. It was March and she was told maybe they would be paid in December 2015.

We arranged for my parents to travel from the rural area where they live to the urban area where my husband and I live. We contacted a friend who gave us a loan on an interest basis. We took my father to the reference hospital to meet the eye, nose and ear doctor as recommended.

There they did tests and my father was sent to do a CT scan. When we got the results our lives changed. He had a brain tumor which was cancerous, they said.

Back in the village we know of cancer as a disease for the rich. Otherwise, for the rest, it means dead. Some say cancer is a mysterious illness which affects people who have committed some sin and is used as a payback.

My poor father sat there and started recounting the story of his life, asking where he had gone wrong. What did he do to deserve this?

I was devastated. I cried all night. I went to the hospital to find out what treatment options were available, if there were any brain tumour survivors I could meet, just any basic information about this condition.

There was nothing.

### Hear my cry for help

I went to a cyber café and started doing research on the Internet. I wrote to over 20 organizations I came across on that day. Finally, Kathy Oliver at the International Brain Tumour Alliance heard my cry and was the only one who answered and wrote back to me. I started



Above: Irene's father, Ngong Jacob Younyi, who was diagnosed with a brain tumour in Cameroon and who is the inspiration behind Irene's tireless work for the Cameroonian brain tumour and cancer community

communicating with Kathy and exchanged my experiences with her.

My father's radiotherapy and chemotherapy every day was very challenging. People came to the hospital at 5.00 am and waited until about 5.00 pm. The waiting queue is long; the

waiting environment not conducive for patients or caregivers. The radiotherapy machine breaks down for over a week or more. There is just a single radiotherapy machine in Cameroon for our entire country of 18.8 million inhabitants. And only two chemotherapy centers.

Every day at the radiotherapy centre was different. We met new faces, new people in shock, as they started their therapy. Many people said they came to the centre for advice. Some said they are the caregiver, while in reality they are, in fact, the patients. They do not want to be associated with the disease of cancer, even at this stage.

### I learn about the value of patient and caregiver support

After two sessions of radiotherapy, we were given a list of medication to buy for my father. I made a shopping list. I went to every pharmacy in town and looked at their prices for the drug we needed. The price difference was amazing. In one pharmacy, the medication cost \$13 and in another it cost about \$5 or even less. I brought this information back to the other patients the next day. It was nothing much in the way of information but I saw so much joy on their faces when they



Above: Irene giving a presentation on brain tumours in Cameroon at the IBTA's Second World Summit of Brain Tumour Patient Advocates held in Sitges, Spain last year

had these details. From then on, everyone came to me with all of their questions and worries. Just like that we started a group. We shared our stories as caregivers and patients.

I downloaded videos on cancer and shared the videos with them. We spoke about survival and treatment methods.





Above: Irene Azong-Wara and IBTA Chair Kathy Oliver at the IBTA Summit

This talking, sharing and learning changed the environment. It made the long waits for the radiotherapy machine or the doctor worth it. I felt like I was adding value to the lives of patients and caregivers.

#### Communicating the Cameroonian way

Then I noticed that more people related to the videos and the talking and discussions. Reading never really works. Many of our Cameroonian people are used to story telling and visuals, such as drama or telling a story through a dance or a song.

I think that in our country, especially in the rural areas, and in our culture this will be the best way to create awareness about brain tumours.

I would like to have a mobile stage which we can build at every location. Using music and drama on stage to raise awareness of brain tumours (and other cancers) could change many lives. We could have survivors giving their testimony. Maybe they will feel like celebrities on stage. Projecting a movie or documentary in the village square will stick in the minds of people. It will push them to participate. They will become advocates without even knowing.

We want to impact our communities using the best methods which they will relate to.

Advocating for cancer patients and caregivers has helped me understand my

own culture better. Creating awareness needs an understanding of people, their culture and backgrounds. I asked myself many times: "How do I get all of these unique people to participate in the same activities and yet yield some results?"

I spoke to Kathy at the IBTA about these thoughts. She arranged for a video for our Cameroonian brain tumour patients to be created at the IBTA World Summit of Brain Tumour Patient Advocates in Spain last year. Summit participants – the leaders of brain tumour patient and caregiver organisations from 27 countries around the globe – recorded video messages sending their support, hope and love, and wishing brain tumour patients and caregivers in Cameroon courage and luck.

They were just short messages of only a minute or so from each person. But when Cameroonians watched the video it had a great impact as they could see that so many people from all over the world are working hard to make a difference. I would like to take this opportunity to personally thank all of the participants at the 2015 IBTA Summit who contributed to the making of this video.

### Many challenges ahead

Our challenges for brain tumour and other cancer patients in Cameroon are many. There is a lot of hard work to be done here. Patients need to understand their illness and find a positive way of dealing with it. Quality of life here is completely different. All the patients want is to finish their treatment and leave the hospital. Caregivers have a hard time dealing with their loved ones who are diagnosed with cancer.

With our awareness programme we hope that we can have a good understanding of both the patients and the caregivers in relation to their educational backgrounds, culture and religion, which are key factors.

With my father it has been a bittersweet relationship. It is so challenging when dealing with the elderly who have difficulty coping with change and getting out of their comfort zone. Yet there is hope.

### What we want to do for patients and caregivers

We want to be able to make videos, explain what cancer is, what its causes

are, the crucial importance of early diagnosis and prevention methods. We want to do all of this in the local languages and in layman's terms.

We want to talk about complementary treatment and treatment methods. We want to understand about the importance of certain vaccines which can reduce the potential of some cancers in the future. We want to talk about good hygiene which plays an important role.

We want to write all of this down in songs and get people to dance about it. This is how our people will understand. This is how our people will remember what it is important to do.

We want all the children to hear about other children with similar cancers who have survived. We want people to dance cancer, sing cancer, talk cancer, think cancer, wear cancer. We want people to change their lifestyles to avoid and/or prevent cancer if they can.

My journey as a caregiver to a brain tumour patient has motivated me to make a change in my country so that more families can have access to information. I want to change the stereotype about cancer. I don't want people to think that it is only some kind of witchcraft or revenge for a sin or that it always needs to be a death sentence.

### Jacob's Hope Foundation

After the IBTA Summit, I created a foundation named after my father: Jacob's Hope Foundation for Brain Tumors and Other Cancers. Our mission is to create awareness through advocacy groups around Cameroon.

The journey has been an amazing one so far. We are very young as an organisation and need a lot of support. Our community has a culture of storytelling. We want to use our culture to create awareness and raise funds. We want to use videos and short documentaries, drama, and photography especially in the rural settings.

One of our future projects is to provide women with cancer with a beauty make-over. We want to offer wigs, makeup and clothes at the centers. We are going to take photos of these women (those who permit us to do so) and give the pictures to them and the hospitals. These pictures will say: "I am a survivor and there is hope."

We have no funds yet to make this happen. Our aim is to start with making videos and documentaries which can be viewed in open air spaces in the rural areas.

We need all the support we can get. The IBTA has given me a chance to impact lives in my country. I will not stop until I have achieved my goal.

We send our love and gratitude from Cameroon.

### **IRENE'S WISH LIST**

Irene has created a wish list to help her organization in Cameroon provide audio-visual information and support to brain tumour and other cancer patients in her country. If you or someone you know can help provide any of these items, please contact Irene at ngong.irene@gmail. com or by phone on: 0023 777 344981 or via Facebook at https://www.facebook.com/lacobs-Hope-

Foundation-for-Brain-tumours-andother-cancers-1735452683351613/ You can also contact the IBTA at chair@ theibta.org or visit www.theibta.org for a link to Jacob's Hope Foundation.

Awareness-raising items: A mobile stage, projector, laptop computer, speakers, video camera (all to create videos, documentaries and photographs to raise awareness about brain tumours and other cancers), any T-shirts with brain tumour information, any pens, any children's books/toys and any clothes.

Personal hygiene and healthcare items for patients: toothbrushes, toothpaste, sanitary pads, post-mastectomy breast forms, protective creams for radiotherapy, food supplements, high calorie drinks and vitamins

## Grand Union Canal Walk



BRAIN Tumour Research's Annual Grand Union Canal Walk took place on 26 September 2015 in the United Kingdom and attracted more participants than ever, with over ninety people on the day. Walkers of all ages and abilities took on the eleven-mile route – and were even joined by a few four-legged friends! Fun and laughs were had by all and children received special Brain Tumour Research medals for their achievement. A distance of 1,593 kms was walked and donated to the IBTA's Walk Around the World for Brain Tumours.

## JACOB'S HOPE FOUNDATION



We are a new advocacy organisation for brain tumour patients and people with other cancers in Cameroon, Africa.



We educate survivors and caregivers on nutrition and quality of life.



We help establish advocacy groups in our country.



We provide information and raise awareness of the challenges of brain tumours and other cancers in our Cameroonian society by using colourful visuals so that people can absorb and remember information which will help them.



We have a Facebook page - search for Jacob's Hope Foundation

You can phone us on 00237 677 344 981 You can email us at: ngong.irene@gmail.com





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Opening of the first eight sites in five European countries starts in the second quarter of 2016.

### Contact

Vassilis Golfinopoulos, EORTC Medical Director spectabrain@eortc.be



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### An interview with David Arons, Chief Executive at the National Brain Tumor Society, United States

David Arons has worked at the National Brain Tumor Society since 2011 and in July 2015 was appointed as its Chief Executive. A trial lawyer by training, David is also a seasoned patient advocate and author. Here, he shares some of his thoughts on his advocacy work with "Brain Tumour" readers.

IBTA: David, what inspired you to become active in the brain tumor community?

David Arons: The brain tumor community is a community of heroes that needs help amplifying their voices. I wanted to bring to the National Brain Tumor Society (NBTS) my background as an advocate to help and empower members of the brain tumor community to have a voice in the policymaking process and to pursue a cure together.

### IBTA: Please briefly describe your role at the National Brain Tumor Society.

David: As Chief Executive Officer, I lead our extremely talented staff. My specific role is to advance NBTS' strategy to defeat brain tumors by funding innovative research, advocating for public policy, convening stakeholders including industry, and empowering patients and caregivers. I am also responsible for making sure NBTS is a strong and accountable charitable organization that provides a memorable, positive experience for anyone collaborating with our organization.

## IBTA: What other work were you involved with before you became active in the brain tumor community?

David: Previously I worked at the American Cancer Society, and prior to that, I worked as a trial attorney. I was also the co-founder and co-director of the Center for Lobbying in the Public Interest. I have been involved in non-profits for most of my career, and believe in the power of not-for-profit organizations to help and transform our society.

IBTA: You are the author of several books about patient advocacy. What three, short pieces of advice would you give to someone just starting out in the patient advocacy field?



Above: David Arons

David: I would say this:

a. Know that your voice counts. Whether you are advocating for changes to laws or advocating for improvements in research or patient care - it is important to speak up on behalf of the brain tumor community about ways to make constant improvements. b. Be authentic. Bring stories and data that truly validate and illustrate the problems for which you advocate. Also present viable, feasible and sustainable solutions to those problems. c. Be local and personal. People in power have hometowns, their own personal lives, and networks. Effective brain tumor advocacy aims to demonstrate how anyone is a stakeholder in the fight against brain tumors.

IBTA: What has been the most challenging part of your work at NBTS to date?

David: Trying to demonstrate the appropriate amount of patience with the research process, while at the same time, being "impatient" as

a patient advocate who wants, and frankly expects, new and better treatments faster.

IBTA: What is the most rewarding/ satisfying aspect of your work at NBTS? David: All the relationships that I have formed with so many terrific people around the world, and of course, the outstanding group of teammates at the National Brain Tumor Society.

## IBTA: Briefly, what are your thoughts on how clinical trials should be changed to reflect the unique challenges that brain tumors present?

David: We are very interested in the concept of adaptive design for clinical trials that can evaluate combinations in multiple testing arms. This is why NBTS is supporting the GBM AGILE trial. We also are leading an effort to improve clinical trial endpoints measured by imaging and clinical outcomes assessments. With the Jumpstarting Brain Tumor Drug Development Coalition's imaging steering committee, we have achieved a new global protocol for standardizing the acquisition of imaging data in brain tumor clinical trials.

### IBTA: How do you cope with the pressures that exist with advocacy work?

David: Of course, there are pressures in every type of work. I choose to focus on the many wonderful relationships with people committed to the brain tumor community, and our many results and accomplishments toward better treatments. I also get so excited about the evolution of NBTS. Those elements truly help me

overcome any potential or real pressures.

### IBTA: How do you relax? Do you have a hobby or a sport with which you are involved?

**David:** I have three young children, so when I'm not working I'm spending time with them and enjoying being a dad. You can guess that I'm constantly in demand for my kids' hobbies.

IBTA: What would be the first three items on your wish list for brain tumor patients and their families?

#### David:

- 1. A cure
- **2.** A health care system that really delivers excellent care to all patients regardless of where they live
- **3.** That people know the National Brain Tumor Society is here for them. ■



**Above**: David Arons discusses brain tumour research and presentation material with US neurooncologist Dr. W.K. Alfred Yung at the annual National Brain Tumor Society Scientific Summit

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The 2016 International Brain Tumour Awareness Week is from 22nd - 29th October.



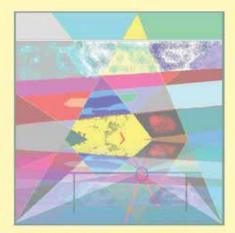
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## When a parent has a malignant brain tumor: an innovative weekend camp for families

### Mary Lovely, PhD, RN, CNRN and Abigail Levinson Marks, PhD United States

THE Milton Marks Neuro-Oncology Family Camp (MMFC) is an annual weekend camp retreat, providing respite and community for families with children, where one parent has a malignant brain tumor.

### Milton Marks' legacy

In 2010, Milton Marks III was diagnosed with a malignant brain tumor and began a two-year journey - along with his wife and three young children - that profoundly changed their lives. After Milton's death in 2012, his wife Abigail (a clinical psychologist) imagined a camp where families like theirs could find respite from the demanding and devastating day-to-day realities of living with brain cancer. Abigail also recognized the importance of establishing a community to combat the social isolation that is often central to families' experience of living with this disease.

Abigail presented her idea to Margaretta Page, Milton's nurse at the University of California San Francisco Medical Center (UCSF), and she - along with the UCSF Neuro-Oncology Department's chair, Susan Chang, MD - were enthusiastic about the idea. Nurses, doctors, social workers and other interested members in the community established a committee and the project moved forward.

#### Two camp weekend sessions

Two annual camp weekend sessions have taken place so far - in October of 2014 and 2015. This year's camp is scheduled for October 6th to 9th, 2016. Each camp has hosted 11 families, all attending free of charge, with children ranging from three months to 21 years old. Camp is held for three days in a beautiful camp setting, Camp Newman, north of Santa Rosa, California. Evaluations, done by the participants, exhibited overwhelmingly positive responses



Above: Abigail and Milton Marks with their children. After a brain tumor journey with her husband, Abigail Marks established the Milton Marks Neuro-Oncology Family Camp (MMFC)

about how this camp helped the family. At the final circle, the staff and campers were all very emotional having been part of such a meaningful experience.

### Community spirit and compassion prevails

MMFC helps relieve family stress and allows time for respite. The weekend retreat provides a chance for a family to have fun together, in a natural environment, where basic needs are already provided. There is no food to cook, and no laundry to do. Camp staff constantly look to support and even pamper family members whenever possible during the weekend. Campers experience being cared for by a community wanting to support them in being able to escape the normal confines of illness, even if just for the weekend. Some families have described how it is the first time since diagnosis that they felt comfortable receiving help - for their children, and for themselves.

A key ingredient to make everyone feel safe at camp is planning for the unique and varied needs of brain tumor patients. The medical care staff, which includes nurses, doctors, volunteers, and psychologists, prioritizes patients who may be physically or cognitively impaired and need close supervision. Patients are often unaware that they are being closely monitored. Families can feel comfortable engaging in their activities and don't need to worry about their loved one.

#### Camping fun and camaraderie

The weekend features traditional camp activities: campfires, s'mores (a marshmallow, graham cracker and chocolate treat roasted over the campfire), singing camp songs and swimming, all of which build community and are lots of fun! Families work on art projects together that help them learn more about themselves and their relationships as a family. Kids spend part of each of the three weekend



Above: Saturday evening around the campfire for family and staff

days in a "camp within a camp" where they have a full program with other campers their own age and counselors trained to work with children whose parents have cancer.

Parents can participate in support groups with other patients or caregivers, take workshops, have couples' meetings, enjoy a massage, yoga, or participate in meditation or nature walks. A special ropes course just for caregivers on the final day of camp gives them a sense of their own - and each other's - tremendous strength in the face of huge obstacles. After families return home, they receive a formal family portrait taken by the camp's professional photographer, Nano Visser, and a camp memory book.

A highlight of the camp is how MMFC gives isolated family members a chance to connect to a community of others who are experiencing similar things, a sense of connection and support. Families attend from hundreds of miles away. Many families have not met others who have lived with a brain tumor. They have the opportunity to interact and share their experiences.

Parents sit quietly and talk together until late into the night. Children truly enjoy meeting other children who carry the same burden they do. From the beginning of the camp, families quickly find each other and relationships begin. Campers also meet staff who understand the stress. The



staff allow them to do what they needed. Therapists, psychologists, social workers and counselors make every effort to provide peace and solace.

## Collaboration ensures a great camp experience for families and professionals alike

Essential to the success of the camp is the unique collaboration with the UCSF Neuro-Oncology department. Families who have attended camp describe how meaningful it feels to have so many of the staff from UCSF at camp for the whole weekend, and to experience how their doctors, nurses, and social workers really "get" what day-to-day life is like for them outside of the clinic. UCSF social workers are able to evaluate participants, identify high-risk families, and continue to follow up after camp. From spending time with them so intensively in this different setting, medical staff have described the new insights they get into their patients' lives.

Patients and families leave camp feeling cared for, with a stronger sense of who they are as a family, how the illness may be impacting them, and how they might want to move forward together. They have made new friends with other families going through the same journey, and with staff who understand them. Many families find that the breathing room camp gives them, leaves them feeling more deeply connected to each other and to their new-found community.

While camps for child patients and their families are available for various pediatric conditions (including pediatric brain tumors), the MMFC is the first camp for families where a parent is ill. The MMFC is an innovative program for family members to come together as a unit, for families to become a community with other families, and to bond with their healthcare professional team. Since the camp provides such an intimate, healing setting, we hope that other places may adopt this model.

For more information about the MMFC please visit www.miltonmarksfamilycamp.org or contact Abigail Marks (iamabby@comcast.net) or Mary Lovely (mary.p.lovely@gmail.com).

# Making hope a reality - how one family is determined to break the scientific 'doom loop' for pediatric brain tumors

Sarah Hamilton
Boston, Massachusetts, United States

CANCER statistics confirm that one in every three of us will be affected by this disease in our lifetime. And I always suspected that one day, way down the road and as my parents aged, that my family would be directly affected. But we didn't expect cancer would impact our youngest of family members.

I remember sitting at work in March 2007, feeling pretty lucky. I had a challenging career, a beautiful home in a suburb of Boston, Massachusetts, a wonderful husband, and my greatest blessing - three beautiful children. I remember thinking to myself: "Thank goodness they are healthy. If one of them had cancer, I would have known by now." Clearly, I was blessed. Everything was going according to plan.

Until it wasn't.

#### News which rocked our world

In early April of that year, school called to let me know that my youngest, Caroline, had just failed her routine kindergarten vision test. Thinking little of it, we made an ophthalmologist appointment and while Caroline's vision was a perfect 20:20, they recommended that we have an MRI to rule out anything further. What we learned on April 26th 2007 rocked our world. Our baby, six years old, had a brain tumor, the most common type – a juvenile pilocytic astrocytoma.

The doctors were optimistic that Caroline's tumor would respond to the 'gold standard' chemotherapy (toxic, archaic drug therapies that had never been proven to be effective, but were the best options that were available). However, it was not so.

After two years of unsuccessfully trying to arrest the growth (and pumping our baby full of 'poison' that had no visible impact on the tumor), Caroline underwent surgery with less than optimal results. With no options left, in 2011, Caroline embarked on a clinical trial, which we believe stabilized her tumor for two years. But in 2013, she experienced another setback, as a hemorrhage took the vision in her left eye.

Again, faced with the heart-wrenching decision of what step to take next, and knowing that the traditional chemotherapy treatments were ineffective, we enrolled Caroline again into a new clinical trial,

Below: Caroline and her two brothers are in this together



which she has been following for the past two years and which we believe is having a positive impact on the tumor progression.

And through it all, Caroline endured these injustices and the impact that it had on her physically, socially and emotionally with an amazing attitude, never losing hope and without a single complaint.

Since Caroline's diagnosis, I have learned a lot. As discouraging as it was to learn that our daughter had brain cancer, it was even more horrific to learn that the frontline, 'gold standard' treatments were over 30 years old, not effective AND there was no research in the pipeline to improve this situation. It was with this realization that our family embarked on the biggest project of our lives - not just saving Caroline, but making sure that future generations of children won't have to endure the same toxic and ineffective treatments.

### Breaking the scientific 'doom loop'

Along with Caroline, our family is determined to help break the scientific 'doom loop' (no funding = no research, no research = no funding). We began raising funds early on in our cancer journey, and

over time our efforts have snowballed and inspired other families to do the same.

Our fundraising efforts for A Kids' Brain Tumor Cure Foundation (formerly the PLGA Foundation) have helped scientists discover the targeted therapies which are being tested in the two clinical trials that Caroline underwent. Without these options, we would have had no hope. But together we are making a difference.

Caroline began high school this year. While she continues to notice the differences between herself and her peers socially, and struggles with academic challenges, especially in math and science, she inspires her two brothers, her parents and everyone she meets with her never-ending positive outlook and passion for changing the journey for future children diagnosed with brain cancer.

It will take a herculean effort to get the attention of major pharmaceutical companies and the national institutes of health across the globe to focus on this 'orphan' disease. But we will continue fighting continue chipping away at the funding gap so that scientists can continue to forge ahead, bringing hope to all children who are diagnosed with a brain tumor today and tomorrow.



Above: Caroline Hamilton's family says: "Never lose hope!"

As individuals, we will make a difference. Uniting with others, we will find a cure.

For further information about A Kids' Brain Tumor Cure Foundation, please see http://akidsbraintumorcure.org



### Brain Cancer Got Me Thinking an art exhibition showcasing the work of the Canadian brain tumour community

Rosie Cashman, Nurse Practitioner
British Columbia Cancer Agency, Canada, and IBTA Advisor



IN October, 2015 (Canada's Brain Tumour Awareness Month), the Patient and Family Advisory Council of the British Columbia Cancer Agency chose to raise awareness about brain tumours while celebrating the talents and creativity of the brain tumour community through an art show. The name of the show – 'Brain Cancer Got Me Thinking' – was taken from a work of art created by a patient from his radiotherapy mask.

The inspiration for this idea came from the inaugural IBTA Summit meeting in Lafayette, California in 2013. Rosemary Wormington from Brain Tumour Support in the United Kiingdom shared her story of a successful art show that she had helped to organize for brain tumour survivors and their loved ones in Britain.

Taking their lead, we asked anyone affected by a brain tumour diagnosis – patient, family member, friend, health care professional, adult, child – to submit a work of art, in any medium, along with



an artist's statement about how he or she was affected by a brain tumour.

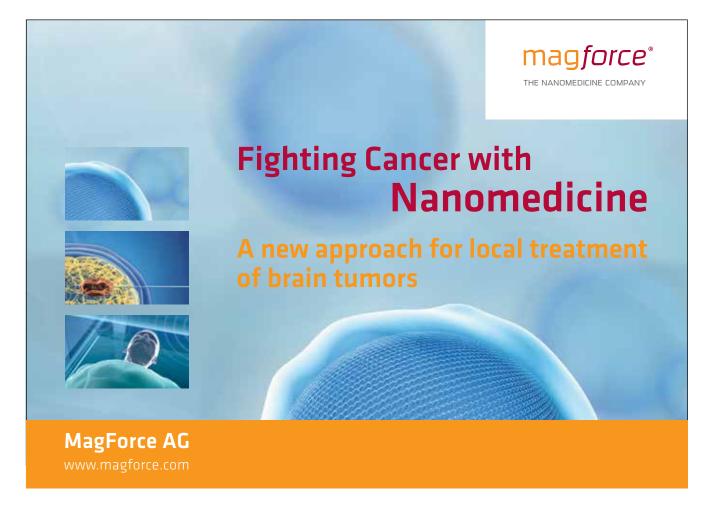
Twenty-two artists submitted works of art in a range of media. A jury composed of British Columbia Cancer Agency staff, patients and professional artists selected 30 works of art for a public exhibition which was held at the Visual Space Gallery in Vancouver from October 7-13, 2015. The artists' stories, in combination

with the art, provided a remarkable glimpse of the resilience of the spirited individuals who make up the brain tumour community. The photos here capture some of the excitement of the show.

The art show was made possible through the generous support of the Brain Tumour Foundation of Canada and the Visual Space Gallery.

A wonderful video of the art works is available at https://www.youtube.com/watch?v=0bemEWZ4|xc =

For more information about the British Columbia Cancer Agency, see www.bccancer.bc.ca For more information about the Brain Tumour Foundation of Canada see www.braintumour.ca For more information about the Visual Space Gallery see www.visualspace.ca



## To Trifinity and Beyond!

Determined volunteers test their endurance to the limits to raise funds for supporting children in South Africa with brain and other tumours

Two close friends in South Africa - Glenn Ambrose and Bonita Suckling - decided they wanted to make a difference in the lives of children with cancer while having some "fun" at the same time.

IN 2008, Bonita Suckling's world was rocked with the news that her only son, Jed, was diagnosed with terminal brain cancer (anaplastic astrocytoma). Doctors told her that Jed, who was four years old at the time, had just months to live.

After three major brain operations, 35 sessions of radiation and experimental chemotherapy, Jed passed away just three years later in his mommy's arms. Overwhelmed with grief, Bonni spent months soul-searching. She made the inspirational decision to turn her pain into power and do something positive to honour her little boy's life.

Bonni and Glenn set themselves a challenge to raise funds and awareness for children living with cancer in South Africa. They would run the Kilimanjaro marathon and endure the African heat. They would then climb Mount Kilimanjaro and do the South African FULL Ironman (3.8km swim, 180km bike ride and another full marathon of 42km). They would then complete the world's largest ultra marathon - the 89km Comrades Marathon.





Above: Glenn and Bonni at the summit of Mount Kilimanjaro with their team. From left: Glenn Ambrose, Arika (Assistant Guide), Bonita Suckling, Michelle Pauly (fellow climber) and Innocent (main guide)

All in the space of three months.

Perhaps now is a good time to let you know that neither are great sportspeople but both have the stubbornness and mental motivation to complete the "mission", no matter how daunting!

How did Trifinity Challenge get its radically cool name? "Tri" comes from the fact that both Glenn and Bonni are "trying" to make a difference. "Infinity" is significant because the cartoon character Buzz

Left: Bonni and her team built this fort out of stones from the mountain – each rock representing a child back in South Africa who had fought childhood cancer or was still fighting. Each rock placed was an emotional experience for the team as it represented the memory of a child or a little soul still fighting to survive. It was a heart-breaking experience for Glenn and Bonni.

Lightyear was Jed's favourite cartoon and he loved Buzz's catchphrase: "To Infinity and Beyond!". When you are a parent, your love for your children is also infinite.

Glenn and Bonni have already completed phase one of the Trifinity Challenge with the marathon and climb done. They went "To Infinity and Beyond" for what they are both passionate about and for what is making a difference in the lives of children with cancer.

Bonni said: "When you've lived through the unexpected death of someone you love, your heart has already been pushed too far, even beyond the limits, and now it's time to do the same with our bodies."

The journey to the summit of Mount Kilimanjaro was one Bonni will never forget. She says it was by far the greatest accomplishment for her personally.

While climbing Mount Kilimanjaro, Bonni Suckling kept a blog. Here is an excerpt from it which was written on the day she and her team reached Kilimanjaro's summit.

MY head is pounding and I have taken two headache pills and it is still throbbing. I am tremendously nervous. I blew my nose into a Wetwipe and felt the familiar release of blood clots giving way. We start the climb on a slope of loose gravel and I almost immediately start feeling cramps in my tummy. My first bout of uncontrolled vomiting starts about three hours into the summit. At this stage I believe there is absolutely no way I will manage to stick with Glenn. He is looking so strong, whilst I am suffering nausea, tummy issues and my head is aching. The higher we climb the worse I start feeling...I have acute mountain sickness. I make a mental call that at Stella Point I will turn back - I just need to make it to that point...When we finally see Stella Point at 5685m, I am overwhelmed with emotions. I am also the sickest I have ever been in my adult life. Stella Point is about an hour down from the summit. One hour Bonita... One hour...

I have very little memories of Stella Point but I know the certificate you get for reaching this point is blue. As I take my first step towards Uhuru Point (the summit), I remember the colour of the certificate is gold - the same colour as the childhood cancer ribbon.

I am dizzy, the pangs of nausea still clawing in my stomach; but somehow with the support of Glenn I manage to slowly take one step at a time and we finally reach the summit.

Is THIS heaven?

My chest has closed up, my heartbeat is racing, I am sleepy and I feel like I have a mother of a hangover. The panic inside me was almost about to explode into shrapnel of emotions.

Our water was frozen but the last thing either of us wanted to do was eat or drink. I wiped my tears onto my jacket and they froze there as if to mark the occasion. Under the red moon, above the clouds, we celebrated our victory.

At the highest point in Africa, the glacial ice cliffs towered over the land with such grace and beauty. We soaked it up and together with my close friend I finally felt a small sense of peace.

To read the entire unedited version of Bonni's blog please go to: www.trifinity4childhoodcancer. blogspot.co.za To learn more about Bonni's and Glenn's efforts please visit their page on



backabuddy:



Above: Bonni feeling the effects of altitude sickness



Above: Stella Point. The certificate for reaching this point is blue. Bonni used this as her motivation to get to the Summit and get the gold certificate. Her mental justification was that the gold ribbon represents childhood cancer.









Above: The Kilimanjaro Marathon: Bonni and Glenn decided to run a 42km/two day race before they climbed Mount Kilimanjaro - just to add to the crazy adventure!

Left: The view from the Summit of Mount Kilimanjaro - is this Heaven?

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## The International Low Grade Glioma Registry

Dr Elizabeth B Claus, Professor and Director of Medical Research, Yale University; Attending Neurosurgeon and Director of Stereotactic Radiosurgery, Brigham and Women's Hospital Boston, United States

THE study of relatively rare diseases such as glioma remains a significant scientific challenge.

Traditionally researchers identify the large numbers of participants required for such studies through use of population-based or hospital-based tumor registries. Each registry includes only a small number of potential study subjects making the study prohibitively costly, labor-intensive and potentially unavailable to persons from regions or countries without registries.

The good news is that the development of secure web and smartphone-based research tools along with collaboration with patient organizations such as the International Brain Tumor Alliance (IBTA) allows scientists to identify, enroll, collect data from, and share results and information with patients with greater ease. Researchers benefit from direct contact with a highly engaged group of potential study subjects, while patients and caregivers benefit from access to scientific and clinical expertise and from the opportunity to voice their interest and concerns regarding research undertakings.

The "International Low Grade Glioma Registry" represents one such web-based research effort.

The overall goal for this registry is to gather data for the study of adult patients with low grade glioma (LGG) as well as to provide an international forum for dissemination of information on the topic.

"The management of these patients remains one of the most controversial topics in neuro-oncology," says Dr. Elizabeth B. Claus, the principal investigator for the registry.

She added: "The information needs and life concerns of LGG patients include those noted for high grade glioma patients (such as overall prognosis, how to gain



Above: Professor Elizabeth Claus

information on treatment, and how to interpret genetic results with respect to the patient's own risk as well as that of any family members). LGG patients' needs also include many that differ given the significantly younger age at diagnosis and long survival time."

Access to this information is difficult for many patients, particularly those who receive care outside of centers that specialize in neuro-oncology. Access may also be difficult for healthcare workers who care for a wide range of oncology patients.

"The construction of a web-based LGG information site will provide healthcare providers, patients, and caregivers with a more accessible and standardized information resource," said Dr. Claus who is Professor and Director of Medical Research at the Yale University School of Public Health and Attending Neurosurgeon and Director of Stereotactic Radiosurgery in the Department of Neurosurgery at Brigham and Women's Hospital in Boston, USA.

Dr Claus has worked extensively in cancer epidemiology and is currently



Above: Picture this: a smartphone app for low grade glioma is under development. It will collect and track common symptoms of glioma treatment including fatigue, cognitive difficulties, sleep disturbances, mood changes and reduction in physical activity.

developing cost- and time-efficient web- and smartphone-based recruitment strategies to be used in the study of brain tumors. She has recently received pilot funding from the American Brain Tumor Association (ABTA) and the National Brain Tumor Society (NBTS) to commence development of the registry.

Traditionally, gliomas have been classified by the World Health Organization (WHO) as grade I to IV (1-4). Adult grade II tumors (low grade gliomas or LGG) have included astrocytomas, oligo-astrocytomas (mixed gliomas) and oligodendrogliomas.

Researchers recently developed a new molecular genetic method to reclassify such gliomas based on three glioma tumor alterations: TERT promoter mutation, IDH mutation and co-deletion of 1p and 19q. This classification method generated five glioma subgroups: triple-positive (containing all three alterations), IDH mutant only, IDH and TERT mutant, triplenegative and TERT mutant only.

Each group has unique clinical features (such as specific ages at diagnosis) as well as specific additional tumor and germline (inherited) genetic alterations.

"Insufficient data exist for LGG across these different subtypes and hence the need to undertake a focused study of LGG to better guide patients," said Dr. Claus. "Genetic information can lead to a better understanding of glioma risk as well as improved selection of treatment for glioma patients. In this study we plan to look at inherited genetic changes to determine whether there is any relationship between such changes and glioma risk. In addition, we wish to study genetic and molecular characteristics of glioma tumors to determine whether we can better predict patients' response to treatment."

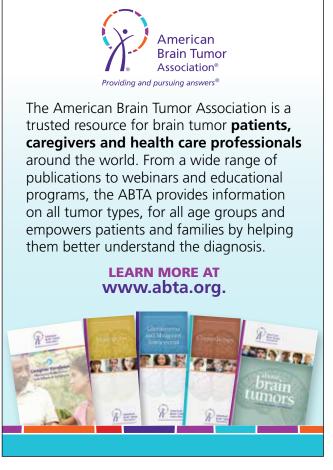
As part of this registry, patients will be asked to provide a copy of their pathology report to confirm their diagnosis. A saliva sample (by mail) as well as a tumor specimen sample will then be requested so that associations between genetic and molecular markers and LGG risk as well as outcomes may be studied.

In addition to learning more about the genetics of glioma, the study hopes to better understand the symptoms associated with treatment. A smartphone app is under development and will use surveys and phone sensor data to collect and track common symptoms of glioma treatment including fatigue, cognitive difficulties, sleep disturbances, mood changes and reduction in physical activity. Some participants will be asked to keep a health or activity diary while others will be invited to participate in a physical exercise program. The information gathered from these efforts will be used to learn what can be done to improve symptoms reported by low grade glioma patients.

The study is expected to open in late summer 2016. An introductory video on the study is available at https://www.youtube.com/watch?v=cbF5LplY5dA . Interested patients and caregivers may contact Dr. Claus at glioma@yale.edu for further information.

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





## A short history of the last fifteen years of glioma treatment in Hong Kong

### Dr Danny TM Chan, Neurosurgeon

Otto Wong Brain Tumour Centre, The Chinese University of Hong Kong

IT was 15 years ago when I was still a neurosurgical trainee. Glioma was an orphan disease. It was rarely heard about in journal clubs or annual scientific meetings.

"It is a deadly disease. No matter how much of it the surgeon has removed, it comes back very soon," I was told. This belief overshadowed the medical field. Radiotherapy was only palliative, if not ritual. There was essentially no chemotherapy available because no agent had shown any positive convincing evidence. Glioma received little attention in the profession, let alone the community.

I talked to the wife of a middle-aged man with glioblastoma at recurrence. She was shocked, learning for the first time his limited prospect for survival. I was deeply sorry for him and for her. Her disappointment is still vivid every time I recall our conversation.

An intense hope for a better standard of care for this group of patients has since been fostered.

#### At the turn of the century - 2000

In the year 2000, there was a shift of belief about the aim of surgical resection in treating glioma. A collection of evidence grew, showing that maximum safe resection improved the survival rate. Neurosurgeons revised their objective of surgery from diagnostic biopsy or certain extent of debulking to maximum safe resection. Knowing the infiltrative nature of the tumour, surgeons take on a certainly demanding job to balance between maximum resection and safe surgery.

Awake craniotomy and mapping techniques are two essential surgical elements. Professor Mitchel Berger, world renowned expert in brain mapping and glioma surgery, was invited to Hong Kong in 2003. He brought these techniques



Above: Dr Danny TM Chan

to every neurosurgeon in a workshop. In 2010, he re-visited Hong Kong for the second workshop to consolidate the application of the techniques.

#### From 2001 to 2008

In 2001, temozolomide was launched in

Hong Kong. The Prince of Wales Hospital was the first and the only center using the drug for recurrence of malignant glioma. The treatment has instilled hope in every desperate patient. The safety and efficacy of temozolomide was published in the Hong Kong Medical Journal in 2005. This was a landmark year for neuro-oncology.

Temozolomide was the first chemotherapy showing objective survival benefit in glioblastoma in a randomized trial. However, the chemotherapy was not funded under the universal health care system in Hong Kong. Most of the patients (50-70%) were not able to afford the drug or to enjoy the benefit of it. This created a difficult situation when there was a treatment option, yet without a safety net for everyone. Instead of being positive, this created a rather discouraging psychology among those who were not able to afford the chemotherapy. Sadly,

**Below**: Dr Danny Chan at one of the Braintrekking events in Hong Kong





**Above**: Look how Braintrekking has grown! 416 trekkers finished the 3.5 km-walk at the Peak of Hong Kong on 25 April 2015. One of the guests of honor, Deanna (the first guide dog in Hong Kong) attracted 11 more dogs to join the Braintrekking event too!

during that time, not everyone was able to enjoy the standard of care in Hong Kong. Advocacy voices from the profession and from the patient community needed to be made to the health care provider.

#### On the awareness-raising front

During the Chicago Society for Neuro-Oncology (SNO) meeting in 2007, I was attracted by the event of "Walk Around the World for Brain Tumours", which was being promoted at the International Brain Tumour Alliance's (IBTA) booth.

We organized our first Braintrekking event for this under the banner of "Hong Kong – Walk Around the World for Brain Tumours" on 27 October 2007. It was a 10 km walk from the Mid-levels of Hong Kong island to the Peak and then back to Central.

A total of 178 trekkers donated 1780 km to IBTA that year. This annual community awareness program has been well received since then. So far, Braintrekking has donated more than 12,000 kilometers' worth of mileage to the IBTA's global Walk Around the World for Brain Tumours.

#### 2009 to 2010

The Chinese University of Hong Kong (CUHK) commissioned our group to establish the first brain tumour centre in Hong Kong. CUHK Brain Tumour Centre, together with the Combined Neuro-Oncology (CNO) clinic, was established in

2009. The CNO clinic was a one-stop clinic for glioma patients who would be seeing the radiation oncologist, neurosurgeon and neuro-oncologist in one session.

A year later a psychology clinic was also established to cope with the needs. The centre received a generous donation from a GBM patient's family with a mission to promote local brain tumour services and research.

An annual visiting professorship public lecture, which is named after the late Mr. Otto Wong, was established in 2010.

#### 2011 to 2013

Professional awareness of and interest in brain tumours has grown intensely with more therapeutic options. The Hong Kong Neuro-oncology Society (HKNOS) was established in 2011. With concerted efforts by the profession and the community, temozolomide was granted conditional funding status in 2011 and subsequent full funding status in 2013.

We observed an improving overall survival in glioma patients in Hong Kong, from less than 12 months in 2003 to 15.5 months in 2013. We are very pleased to see this result from the efforts by the profession and the community. However, there are still challenges ahead.

## Into the future of brain tumour treatment in Hong Kong...

The cost of future effective treatments

will be adding up on the expensive backbone therapy of concomitant chemoradiotherapy. It will be difficult to make ends meet in Hong Kong's universal health care system. Solutions, such as an enhanced safety net system or an insurance program, should be sought by the government and the community.

Furthermore, I am looking forward to building a Hong Kong clinical research team to bring about international clinical trials and to organize local clinical trials here.

This will bring Hong Kong's neurooncology to a higher level when we are able to offer more than the standard of care treatment.

Plan your 2016
"Walk Around the
World for Brain
Tumours" now!
For futher
information contact
chair@theibta.org

## Learning how to live

## **Nitesh Mohanty** Mumbai, India

On the morning of 12th January 2007, I woke up to my wife's first epileptic attack. Life was never the same again. It's been eight immeasurably overwhelming years and after being by her side through three surgeries, countless sessions of radiation and chemotherapy, I still find it difficult to comprehend and define our ordeal with a brain tumour. Here is an attempt to share an amalgamation of thoughts - ranging from hope to despair, inspiration to introspection, realization to acceptance, reflection to reconciliation.

This is dedicated to patients, survivors, caregivers, nurses, doctors, friends and family members of the cancer community.

"The truth is, once you learn how to die, you learn how to live." "Tuesdays with Morrie" by Mitch Albom

DEATH to some comes unannounced and for some becomes a companion through a prolonged journey.

We unfortunately can't choose one over the other. Yet with the latter, there's enough time; it prepares you for the inevitable and while doing so, it could mean letting you fulfill all your dreams or making life staggeringly painful. Either way, you learn to live with it, taking each day as it comes with all the uncertainties.

A line that I often use to console myself is: "Everyone has their battles, and this is ours". One can't do much other than accepting certain realities that are hard to comprehend. After a point you stop questioning, crying,

complaining. You eventually

learn that fighting is futile

and it's better to surrender.

Not in a meek or defeated way, but with the vastness of heart which allows you to embrace the NOW, without worrying and frowning about tomorrow.

More than anything else cancer teaches you.

It teaches you to find joy in little things, to make the mundane memorable, to choose every moment preciously, to hold life as dearly as possible. And as you stand by your loved ones, helping them accept that they'll still be beautiful without hair on their scalp... When you realize the importance of platelets... When you sit overnight learning about terms that are alien to you and are soon going to be a part of your everyday conversation... You realize that your life is different from your friends, for whom the promotion, clinching the deal, the salary hike, the next new car, the big holiday are priorities which are so very different from yours.

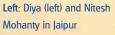
Sometimes you get tired, fatigued, exhausted. But you try not to frown or complain, you try and do everything you can within your means, yearning to live a "normal" life.

You hope there's a friend who'll quietly listen. You wish the family members to be more thoughtful. You pray not to become a liability, a burden to your loved ones. And in spite of desperately wanting to cling

on to life, you learn to accept death.

Not as a stranger but someone who's been a close companion, as with cancer you die a bit every day, silently without anyone knowing about it.

Left: Diya (left) and Nitesh



Yet, amidst the garden of gloom there are enough blooming tales of heroism, of survivors who've celebrated each day, painting it with myriad shades of joy, hope and resilience.

Well, they say, what doesn't kill you makes you stronger. Let's hear those incredible stories too. Let's try not making cancer a hush word. Let's try and be more aware, with a sense of acceptance. Rather than alienating the disease and

those ailing from it, let's learn to embrace them instead of stigmatizing them. Let's try and find new ways of bringing joy and warmth within the dreary and difficult everyday of a distant or a dear one.

Have you ever thought of visiting a children's cancer ward with a boxful of chocolates on your birthday? There are innumerable ways of touching lives. And you could make a difference.

Above all let's learn not to take life for

granted. Don't wait for an illness to knock on your door. Value, appreciate and rejoice in what you have. Because every breath is a blessing. Each day a gift.

This piece was written originally by Nitesh as a Facebook post on World Cancer Day 2016

## Annual Caroline Fund 5K Race (United States)



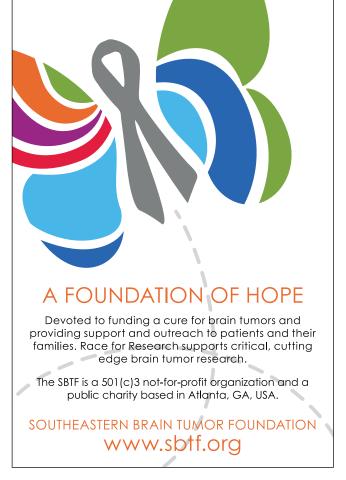
ON Saturday, 12 September 2015 the Caroline Fund held the Second Annual Caroline Fund 5K Race in Caldwell, New Jersey. 781 registered participants ran or walked the 3.2 mile (5 km) route, accompanied by 100 volunteers. \$100,000 was raised with a total distance of 2,500 miles (4,000 km) travelled.

The Caroline Fund is a non-profit organisation established in 2013 in memory of

Caroline Vandemark, who lost her life at 22 to a glioblastoma. The funds and awareness generated from this race support the brain and spine tumour research at the John Theurer Cancer Center at Hackensack University Medical Center, New Jersey.

Find out more about the Caroline Fund at www.carolinefund.org.





## First SNOLA neuro-oncology conference held in Latin America

Marcos V. C. Maldaun, MD, PhD, SNOLA's Founding President São Paulo, Brazil



### www.snola.org

THE Society for Neuro-Oncology Latin America's (SNOLA) first conference, "Update on Neuro-Oncology", took place from the 24th to the 26th March 2016 in Rio de Janeiro, Brazil, and was a huge achievement for the Latin American neuro-oncology community.

With more than 25 international speakers sharing their knowledge, nearly 600 attendees, and 137 research abstracts submitted for the oral and poster awards, we can definitely ensure that our 2018 conference will be magnificent. It is already being planned, will be held in São Paulo, Brazil, and will be called State of the Art in Neuro-Oncology.

During the 2016 Rio meeting we had special moments, such as the awards ceremony, where we rewarded with a plaque renowned names within the different national and international areas of neuro-oncology (pathology, imaging, radiotherapy, oncology, pediatric oncology, and neurosurgery).

Awards were also presented for the best research poster and oral presentations by individuals from all around the world. This was a chance for SNOLA to thank these researchers, as well as encourage them to continue with their good work. SNOLA recognizes the need for and importance of research to develop neuro-oncology around the world.

Furthermore, the quality of the



Above: Dr Marcos Maldaun opens the inaugural SNOLA conference in Rio de Janeiro, Brazil

educational sessions at the SNOLA conference was remarkable, featuring case studies and multidisciplinary experts. There were also "rapid-fire" presentations.

Feedback from attendees could not have been better. It was therefore an amazing experience for the first conference. We thank everyone involved in making the event possible: our sponsors, the organizing committee and the scientific committee.

It was a great pleasure to hold this event for our Latin American society. We are looking forward to SNOLA's conference in 2018 on the State of the Art in Neuro-Oncology.



Above: A full house for Latin America's first neuro-oncology conference

## Did you receive *Brain Tumour* magazine in a personally addressed wrapper?

If you did, then you are on our database. However, if you received the magazine but do not receive our regular e-News bulletins it means that we do not have your email address.

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## FIGHTING AGAINST BRAIN TUMORS TOGETHER

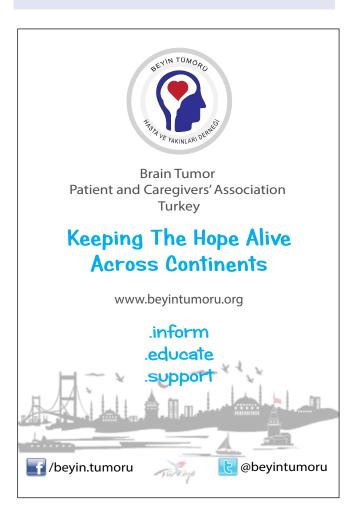
We are pleased to stand beside our friends at IBTA in fighting brain tumors.

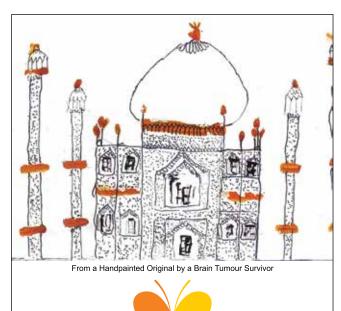
Join the National Brain Tumor Society and the global brain tumor community by helping us find better treatments, and ultimately a cure.

It's Your Fight, It's Our Fight.



### www.braintumor.org





Brain Tumour Foundation

••• of India•••

We have been working since the last 15 years for the welfare of people with brain tumours. Our motto is to help every person with a brain tumour in our country to receive optimum treatment and care irrespective of their socio-economic status.

### www.braintumourindia.org

1129, Homi Bhabha Block, Tata Memorial Hospital, Parel, Mumbai. - 400012, INDIA. Email: btf@braintumourindia.org

## Everything erased and under control: Laia's journey with a DIPG

### Damià Calvet

Barcelona, Catalonia, Spain

OUR daughter Laia left us on 22nd January 2015, when she was 11 years old, after two long years fighting against a diffuse intrinsic pontine glioma or DIPG.

It is known that this disease can't be cured and takes every child diagnosed with it but, step by step, research is opening up hope for treatment options. Sant Joan de Déu Foundation, in Barcelona, has a Childhood Cancer Research Group and, along with other research groups around the world, they're making strides towards containing this disease.

As an affected family, we did what we thought that we had to do: allow a biopsy and also an autopsy, and raise funds to help research. We weren't in time to treat Laia, or other children before her, but we wanted to help treating future cases.

We raised 64,000 Euros to push this research forward, through a micro-donation project, which we called "Everything erased and under control", a phrase we used to say every day with Laia when she took her medicines or before she went into her radiotherapy sessions. This referred to our strong determination to erase the tumour.

In this link you can see a video explaining the fundraising project, in Catalan and with subtitles in English: http://bit.ly/1EeFpbv. The project aimed to raise funds for well-defined needs: buying a disaggregation device for biopsies and a multichannel electronic pipette, and contributing to a clinical assay based on immunotherapy, which consists of "teaching" each individual immune system to identify the bad tumor cells and destroy them.



Above: Laia

Anyone who donated more than 25 Euros received a printed edition of a story called *RETURN*, written by me and which Laia's mother, Montse, and her older sister, Maria, and I decided to share.

Here is the link so you can download and read the story: http://bit.ly/1Agf6Xk. It's only a dream, a way of explaining myself, because in the real world there was never any hope for Laia. The serious disease she suffered was ruthless, completely ravaging her young body. It advanced day after day, obliterating each of her abilities, robbing every last spark of life she had.

What I imagined in my story *RETURN* was Laia returning to us, step by step, overcoming each of the hurdles the disease had put in her path, one after the other, and each one higher and more difficult to clear. It is the imagined story of Laia's return from the deepest darkness she fell into until she was once again fully herself and

we could keep her that way forever in our memories.

Laia was a happy girl, and she made us very happy. And she was also very brave during her illness. We are sure that she would have liked the project we developed in her memory because, after all, it is a way to help all the children who, like her, will have to fight and, in the future, to win against DIPG.

LAIA Calvet was diagnosed with a DIPG brain tumour in December 2012 and passed away in 2015. Her father, Damià, wrote this short story towards the end of Laia's life - "an imagining" as he calls it. He imagines, from Laia's point of view what it would have been like had his daughter been cured of her DIPG and what, in her perspective, her return to normal life would be like: free of the disease, joyful at her regained independence and simply bursting with life, love and hope.

Damià said: "When we were nearing the end, I realized that it would be difficult for me to remember her as she was before the disease. I'd forgotten her voice, her smile, her running through the halls at home, her questions, her bad moods (which of course she had, too), her hugs and her kisses. And Montse [Damià's wife] said the same.

"We hadn't really forgotten, of course, but we were so

caught up in our devotion to her dependence, to the 'logistics of the thing' as I referred to it, that weeks could easily pass in which, between treatments, washings, hospitals and medicines, plus the difficulties of just moving and eating, we were only able to see the sick Laia, unable to see the Laia that was hiding behind that disease and would always be our Laia ...amidst the constant battle against death, it was hard to remember these moments of life. So I began to imagine this 'return'...

## Excerpts from RETURN

...I remember this is how it all started: I got a bit cross-eyed, and I still don't really know why, or what it had to do with being cross-eyed, but from then on we started going to hospitals and seeing doctors and nurses and taking blood and having operations and scans and radio and chemo and all that.

++++++++

...I just said hello! Loud and clear. It even scared me a little, because I hadn't been able to speak for days and days and days. When I first got sick, I still could, of course, and I talked to everyone...But then I started losing my voice. Well, not my voice, the air I needed to get my voice out. First I started speaking more softly and then haltingly, gulping air and forcing it out, one gulp for each sentence or for each word. And in the end I just couldn't speak any more. But now I can: hola, hello, a-e-i-o-u, la-la-la...

+++++++++

... I want to go to the bathroom! I haven't been able to sit on the toilet and pee and poo by myself for a long time. When I couldn't stand anymore, I stopped being able to control that as well. So my parents started putting diapers on me. They never called them diapers; they said pull-ups. They do it to make me feel better, for sure. But diapers or pull-ups, it doesn't matter, I'm taking them off right now and sitting on the toilet, it's about time. And then I'll wash myself too, because they've been giving me sponge baths in bed for a while now and washing my hair in this inflatable thing, like a beach raft, with a hole for my head so they could wash it like they do at the hairdresser. And my hair always looked good. Everyone says I have really pretty hair. Having your hair washed like that is fun the first day, but now I feel like doing it myself, having a shower from top to bottom like I did before I got sick...

**\*\*\*\*** 

...Before leaving the bathroom, I look in the mirror and see that my right eye is in its place. That's where this whole thing started, and I hated it when it was looking the wrong way because I didn't like looking at myself in the mirror. Even though everyone told me I was just as pretty as always, I knew it wasn't true and sometimes that made me sad. But now it's fine because I had an operation and after that I felt better, even though we had to be very careful because it didn't close right and we had to make sure it didn't get red. I look again, no, it isn't red, it's in its place and I can close it properly. I'm really good at raising my evebrows, first one and then the other. It always makes everyone laugh. I raise one... and the other.

I get dressed and walk past my wheelchair, parked in my room. And now I'll go to the kitchen. I'll have one of my peach juices and grab a cookie, which I'm pretty sure I'll be able to chew, little by little. I'm the cookie queen, even though my dad always

tells me that I should eat my lunch or dinner and not have so many cookies. But there are always all kinds of them at home, and he buys them! It must be because he knows I love them. But what I really want is a plate of Mom's food. I've been eating out of a syringe for too long!

+++++++++

I think of all the things we'll have to do. I won't need the wheelchair anymore; we'll probably donate it to the hospital. We'll have to pack up my room, toys, clothes, the sixthgrade books that I followed as long as possible even though I couldn't go to school, with help from my teachers who came to visit. And we have loads of pictures we have to put in albums. We've taken tons but since I got sick we haven't had time to print and organize them. And I want to look at all of them. And while we're at it, we'll probably organize the pictures and videos from when I was little, and from when Maria was little and I wasn't here yet. I'm sure we will.

+++++++++

Now it's time. Close your eyes tight and take a good look at me, in your mind. I'm here, standing and smiling. I'm blowing you a kiss, pressing my hand hard against my lips. Muac! A big one and I'll blow it to you for a long time, because it's for so many people, for all of you. I raise both arms and wave them back and forth to say goodbye. Now I'll turn around and walk that way, you see? Over there. And I'll run and jump like I always do, and don't be surprised if you hear me singing, because it means I'm happy, glad for everything I got to experience. Now I have to go, but I want you to remember me this way, always...

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## The science behind a therapeutic ketogenic diet for brain tumors

Dr. Adrienne C. Scheck and Eric C. Woolf, Neuro-Oncology Research, BBTRC Barrow Neurological Institute, St. Joseph's Hospital and Medical Center, Phoenix; Arizona and School of Life Sciences, Arizona State University, Tempe, Arizona, United States

MALIGNANT brain tumors are a devastating disease due, in part, to the limitations of currently available treatments. Advances in our understanding of the molecular biology of this disease have led to an increase in the number of targeted therapies being studied and while these therapies may prove somewhat beneficial, better and more effective treatments are urgently needed. Newer immunotherapies are being investigated and may hold promise, but to date they have not significantly changed patient prognosis. This is due, in part, to the intrinsic differences in the cells that make up the tumor (called "cellular heterogeneity"). These differences often result in targeted molecules being found on only some of the tumor cells, thus reducing the effectiveness of these treatments.

In contrast, one trait shared by virtually all tumor cells is altered metabolism.

Alterations in the metabolism of cancer cells, what we now call the "Warburg effect", was first described by Otto Warburg in 1927. Simply put, cancer cells metabolize glucose (sugar) differently than normal cells and therefore they need high levels of glucose for energy and to create the building blocks needed to make more cancer cells.

Since Warburg's discovery, metabolism has been of interest in the cancer field, but it often seemed overshadowed by discoveries of genes involved in tumor formation and growth. There is a resurgence of interest in metabolism as a central theme in cancer, and we now know that metabolic pathways intersect and often regulate key components of tumor growth and therapy response. In fact, altered metabolism has been referred to as a hallmark of cancer. The fact that metabolic dysregulation is seen in virtually



Above: Dr. Adrienne C. Scheck

all tumor cells has led to suggestions that this may be a promising therapeutic target.

One way to target metabolism is through the use of the therapeutic ketogenic diet (KD).

### What is the ketogenic diet?

The ketogenic diet is a high fat, low carbohydrate/adequate protein diet. When used for the treatment of epilepsy, tumors or other diseases it must be strictly adhered to and is probably more correctly referred to as "metabolic therapy" rather than a "diet".

Although the KD has a long safety record due to its use as a therapy for pediatric epilepsy, there can be significant side effects if used incorrectly. It should only be done under the strict supervision of a medical professional and with the knowledge of the patient's oncology team.

The KD causes a reduction in blood glucose (sugar) and an increase in blood ketones (ketones are normally made in our body when we break down fat). The reduction in blood glucose is likely to slow the growth of



Above: Eric C. Woolf

tumor cells since they require large amounts of glucose. Normal cells also require glucose; however, normal cells can readily use ketones instead of glucose for energy. In contrast, tumor cells are not "metabolically flexible" and therefore they require glucose.

Thus, the thought was that the KD would "starve" the tumor. To this end we began laboratory studies of the effects of a KD on the growth of malignant brain tumors.

## The ketogenic diet in combination with radiation and chemotherapy

Our early experiments demonstrated that a KD inhibited the growth of brain tumors in our mouse model. While other scientists used caloric restriction in addition to the KD to slow tumor growth, we allowed the mice to eat as much of the KD as they wanted and we still saw a slowing of tumor growth and an increase in survival. Since our ultimate goal was to demonstrate the utility of the KD in the clinic, we tested its effects when used in addition to radiation and chemotherapy

(the standard of care). We found that it not only enhanced the activity of temozolomide, it greatly enhanced the activity of radiation therapy. In fact, when maintained on a KD and given radiation therapy, the tumors disappeared in nine of eleven mice, but radiation alone did not have this effect (1). This was very exciting and spurred our interest to continue these studies and try to dissect how the KD may be working.

#### Other effects of the ketogenic diet

We and others have found that the KD is amazingly pluripotent (see illustration at right). That is, it has many effects on the tumor that far exceed the original idea that it restricts energy in the cancer cell.

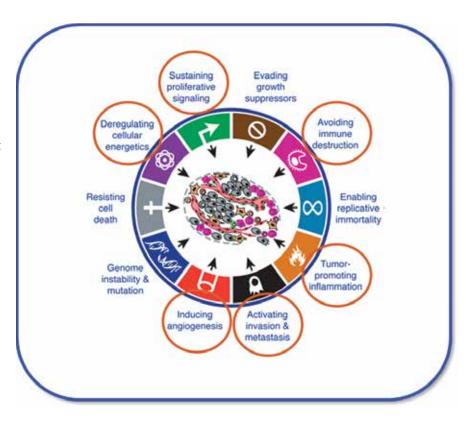
We found that the KD reduces the formation of new blood vessels (angiogenesis) and causes a reduction in swelling around the tumor (edema). This is what bevacizumab was designed to do. It reduces hypoxia and the expression of a gene called hypoxia-inducible factor 1a (HIF-1a). Hypoxia is "reduced oxygen", and tumor regions that are hypoxic are typically resistant to therapy.

In addition, HIF-1a turns on a number of genes involved in turnor growth. It also reduces the expression of genes that may promote the cells' ability to invade normal tissue (2).

Most recently, we have found that the KD has effects on the immune system and it is likely to enhance the anti-tumor immune response in a manner similar to the goal of some newer immunotherapies. In addition to studies using animal brain tumor models, we and others have shown that the addition of ketones to mouse or human glioma cells grown in the laboratory causes the same effects, even in the presence of high levels of glucose. Cell growth is inhibited, the cells are more sensitive to radiation and chemotherapy and they migrate (move) less than cells grown without ketones.

#### In summary

As more studies demonstrate the multitude of effects that altering metabolism can have on tumor growth, particularly in brain tumors, it becomes more apparent that if done correctly, decreasing blood glucose and increasing blood ketones through a properly managed ketogenic diet should inhibit the growth of the tumor while enhancing the efficacy of other therapies and preserving quality of life.



**Above**: The ketogenic diet reduces many of the pro-tumor characteristics that have been called "Hallmarks of Cancer" by Hanahan and Weinberg (Cell. 2011 Mar 4;144(5):646-74).

To this end we, and others, have opened clinical trials in humans to fully test the efficacy of the KD as an additional therapy for the treatment of brain tumors. These studies are continuing, as we try to understand the many effects this has and how to best use this information to enhance brain tumor patient survival.

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## Ed Evans Foundation 'Walk the Vale' Walk



ON Easter Monday, 6th April, 2015, 278 walkers took part in this annual Ed Evans Foundation event in the United Kingdom. With the sun shining, walkers chose either a short six-mile walk or a long eleven-mile walk, both of which took in the stunning scenery of the Welsh Vale of Glamorgan. 1,983 miles were walked and over £2,000 raised for the charity.

The Ed Evans Foundation website is here: www.edevansfoundation.co.uk

# Matthew's Friends: supporting groundbreaking research into brain tumours and the ketogenic diet

## Emma Williams MBE, Founder/CEO, Matthew's Friends for Ketogenic Therapies United Kingdom

After standard therapies to treat his severe epilepsy proved to be of no use to Emma Williams' son, Matthew, she turned to the ketogenic diet for him with impressive results. Now this diet is undergoing clinical trials for brain tumour patients in the United States and United Kingdom in the hopes that it might benefit neuro-oncology patients as well.

The ketogenic diet – or "KD" – is one which is high in fat, supplies adequate protein and is low in carbohydrates. It is very important to note that the ketogenic diet is prescribed by a physician and very carefully monitored by a dietician. No one should undertake a ketogenic diet without medical supervision.

Here, Emma describes her journey with her son and her hopes for the brain tumour community.

MY son Matthew suffers with a catastrophic form of epilepsy called 'Dravet Syndrome'. His seizures started when he was nine months old. He was put on a cocktail of medication that just didn't work, the side effects were horrendous and the seizures soon became life threatening. It was heartbreaking to see him suffer so much.

I found out about ketogenic therapy when Matthew was two years old, by doing my own research. But when I spoke to his neurologist, she told me the diet didn't work, that medication was the best option. She also told me that I would make my son suffer even more if he were to go on this diet. Naturally, I did as the doctor told me and we went on trying innumerable medications which didn't help Matthew at all.



**Above**: Emma Williams (left) with her daughter Alice and son Matthew

#### Seizures take a terrible toll

By this time, Matthew was severely brain-damaged and attending a special needs school. He had hundreds of seizures each week and was on a cocktail of medication. I was now a single mother to Matthew and his younger sister Alice, as the family had broken apart. Alice's life was also miserable, she couldn't bring friends home as Matthew would scream all the time. He was also quite violent towards her, so she spent most of her time getting away from her brother and obviously a lot of my time was taken up looking after Matthew. So Alice missed out on a lot of my attention as well.

As time went on I was told that IF Matthew lived to the age of 12 then he would probably have to be in a residential placement as he would be too difficult to manage at home. My heart was breaking. He was my son and I felt like our time

was running out. I decided that however bad this 'diet' was we needed to try it.

## A ketogenic diet clinical trial for children with drug-resistant epilepsy

Thankfully, Professor Helen Cross from Great Ormond Street Hospital in London set up a clinical trial using ketogenic therapy and Matthew was one of the first children enrolled onto the diet (The ketogenic diet for the treatment of childhood epilepsy: a randomised controlled trial, J Helen Cross et al, The Lancet Neurology, http://www.thelancet.com/article/S1474-4422(08)70092-9/abstract).

Matthew started the classical ketogenic diet when he was seven years old. Within two weeks of starting, his seizures had reduced by 90% and within eight months of being on the diet he had been weaned off all his medication.

The difference in him was remarkable. I got what was left of my son back. He was happy, relaxed, sleeping better and enjoying his life. He did have a few seizures, but they were really short in duration and he recovered quickly. All the side effects of the medications were gone. He and his sister's relationship developed into a loving bond and Alice's life was also turned around. As for the diet, it wasn't as difficult as the doctor had originally told me it would be and it did work. The diet was a little daunting at first but I soon got into the swing of things and Matthew was enjoying his food as he always had done. We didn't have horrendous side effects from the diet and he thrived.

#### Matthew's Friends launches

I knew that other families were also suffering in the same way we had and I believed families had the right to make an informed choice of treatment for their child. I set up the Matthew's Friends charity for ketogenic therapies in 2004. It started off as a parent support group where I shared my story and experiences of using the diet.

Today we have a distinguished medical board, chaired by Professor Helen Cross OBE, the Prince of Wales's Chair of Childhood Epilepsy at Great Ormond Street Hospital. We invest in clinical research, training and educational programmes for professionals and provide funding for NHS ketogenic services around the UK and Ireland. This is all on top of our considerable support services for families.

We have registered branches operating out of New Zealand and Canada and in 2011 we opened Matthew's Friends clinics for ketogenic therapies. With resources extremely stretched in the National Health Service here in the UK, we decided to employ our own dietitians to provide a

service to children and adults who wanted to access ketogenic therapy but where there was no local service for them. It also means that we can undertake case studies while working towards new clinical trials in new areas where ketogenic therapy could prove beneficial.

This is where our work has evolved to include those with a brain tumour.

## The ketogenic diet and brain tumours

Our charity has now partnered with the Astro Brain Tumour Fund in the UK as we fund patients through ketogenic therapy with low grade brain tumours. We are working particularly closely with the Charing Cross Hospital team in London in developing clinical trials in the neuro-oncology area.

Dr Matt Williams (no relation) from Charing Cross has also joined the Matthew's Friends medical board for oncology together with Dr Adrienne Scheck from the Barrow Neurological Institute in the US who has undertaken a lot of research work on the ketogenic diet and brain tumours.

It is very early days, but so far the results we are currently seeing certainly seem to be benefiting brain tumour patients' quality of life. However, a lot more research is needed. We are passionate about this being done and possibly giving brain tumour patients more hope. We are currently fundraising to get these brain tumour clinical trials started.

### Happily into the future

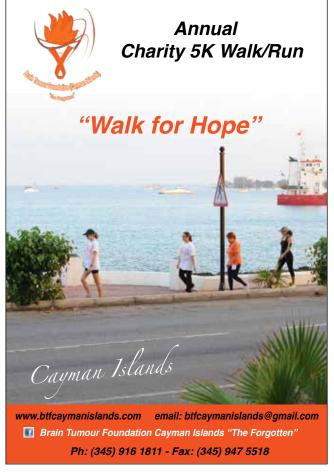
As for my Matthew, he is now 21 years old and still happily living at home with no plans on moving anywhere! He is a happy young man and loves his life and yes, he is a bit of a 'mummy's boy' and I am quite happy with that. The ketogenic diet is not a treatment for life, so Matthew has now been weaned off it and the seizures have not returned. Matthew's sister is currently in her second year of medical school training to be a doctor, inspired by her brother.

For further information about Matthew's Friends, see their website at www.matthewsfriends.org



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## Alicia Pueyo Fund: moving towards a cure for DIPG

## Gloria Garcia Castellvi, Fondo Alicia Pueyo Barcelona, Spain

DIFFUSE intrinsic pontine glioma, DIPG.

As with most of the families affected by this devastating disease, we had never heard these four words until the day when our lives changed forever: the day of Alicia's diagnosis.

Our precious six-year-old daughter had an incurable brain tumor, impossible to remove by surgery, and with no effective treatment except for palliative radiotherapy to gain a few more months with her. It was 2006, and still today - ten years later - there is no cure for DIPG and life expectancy for children affected by this tumor is about 12 months.

### A commitment to Alicia

Alicia didn't beat the odds. After 15 months of fighting the tumour, she left us on November 21st, 2007. From that moment, our family – as well as many others who have gone through this nightmare - strongly believed that our daughter's fight to overcome this terrible disease must go on. We had a commitment with Alicia; we had to keep working to find a cure and giving other children the opportunity she never had.

More funding for research into DIPG was definitely needed in order to make advances in treatment. So the Alicia Pueyo Fund was set up in 2008 with a signed agreement between our family and the Sant Joan de Deu Research Foundation in Barcelona, Spain. Besides promoting research on DIPG, the aims of the fund are also to provide support and information to affected families and to facilitate international collaboration in this field.

Alicia was treated in Hospital Sant Joan de Déu. After her diagnosis, we



Above: Alicia Pueyo, a few months before her diagnosis of a DIPG brain tumour

started to look for available treatments in the best medical centers around the world. But none of them gave us any hope.

Finally, it was in the same hospital where Alicia was diagnosed that we were offered a new and experimental treatment which gave us at least a chance to fight her tumour.

## Willing to change minds; thinking outside of the box

From the beginning until Alicia's last days, Dr. Jaume Mora, her oncologist, and all his team showed us that they were willing to change minds, to think out of the box and to walk down new paths to cure our daughter. Only people like these, willing to face impossible challenges, will be able to find a cure for DIPG. For this reason, we decided to set up the Fund in this institution.

The next step was to decide what to start working on. At that point,

Dr. Jaume Mora proposed that we kick off international collaboration in DIPG research by organising the first international workshop in DIPG. This took place in Barcelona on February 26th, 2009.

In a hands-on environment, a small group of DIPG experts from around the world shared their knowledge, their past failures and their plans and aims for the future. After that first meeting, with many other families involved, others meetings were organized in Toronto, Cincinnati, Amsterdam and Barcelona again. DIPG collaborative research networks got stronger, both in the United States and Europe.

### Research on DIPG moves forward

Meanwhile, Alicia Pueyo's Fund was focused on supporting the Hospital Sant Joan de Deu research group. They started to collect and share tissue samples from autopsies with other groups and to promote biopsies for DIPG patients.

Again, it was necessary to change minds. In 2012, with the invaluable collaboration of Dr. Stephanie Puget, the first patient was sent from Barcelona to Paris to undergo a biopsy. From 2013, biopsy became the standard procedure for DIPG patients in Hospital Sant Joan de Déu. I know that it is a very controversial issue but from my point of view, biopsy is definitely necessary to reach a cure. Without biopsy, there is no tissue for research and without research, the cure for DIPG will only ever be wishfull thinking.

The availability of tissue samples for research brought a complete change of the scenario. Researchers could now better know the enemy, identify

DIPG mutations and understand why treatments for adult GBM failed again and again with DIPG patients. DIPG is a biological entity by itself, different to any other adult or even pediatric brain tumor; it is defined by a mutation in histone H3.

Dr. Angel Montero Carcaboso, who joined Dr. Mora's team in 2010, has done outstanding work with biopsy samples, developing a robust mouse model of DIPG and several cell lines, all of them matching the genetic definition of DIPG. This model is and will be a fantastic tool to test new drugs and delivery methods, like oncolitic viruses and convection enhanced delivery (CED). There are very few models like this one - if any - in the world.

### Collaboration is the key

Of course, as we learned in the first international workshop, all these achievements would have been impossible without collaboration



**Above**: Alicia with her mother, Gloria and brother, Ferran, just prior to her diagnosis

between many research groups around the world. I would also like to mention Dr. Chris Jones from the Institute of Cancer Research in London, UK. Thanks to his work - and seven years after Alicia passed away - we could know all the mutations of her tumor, as a result of the whole sequencing of the autopsy tissue. This was part of a Nature Genetics publication and it meant the world to us.

Currently, Dr. Jaume Mora's team is focused on how to improve blood brain barrier penetration, the use of nanoparticles to deliver new drugs to the tumor and the start of a new clinical trial based on immunotherapy. All of them are exciting and promising projects for DIPG patients of the future.

All of this new knowledge, the international alliances, cell lines and mouse models were unthinkable when Alicia was diagnosed. In ten years, we have moved from being completely in the dark about DIPG to seeing a silver lining. I'm completely sure that with the commitment of affected families and the work of outstanding clinicians and researchers willing to change minds, we will find the cure for DIPG.

We owe it to our children.



## Psychological support for brain tumour patients: the Croatian experience

Valerija Korent, Bacc.Med.Tech., President of Glia and Marta Dumanćič, Mag.Psych., psychologist at Glia – the Croatian Brain Tumour Patients' Association, Zagreb, Croatia

THE treatment of cancer no longer includes only medical care. Psychological support and counselling should be available to patients and their loved ones at any time during and after treatment.

Unfortunately, psychological help in Croatia is not yet a standard part of treating patients with cancer. Many patients often feel lonely and isolated because they think that what they are experiencing is not normal or usual so they feel ashamed to talk about it or ask for help. Patients often feel like there is no one they can turn to who would understand and help them cope with everything they are experiencing. They are often not aware that their feelings and fears are completely normal given the situation.

Dealing with the diagnosis of cancer is very demanding and mentally exhausting. Professional psychological help and support can greatly contribute to quality of life and the patient's motivation for meeting the challenges, resolving problems and dealing with distress caused by illness.

#### About Glia and psychological support

Glia - The Croatian Brain Tumour Patients' Association - helps patients by offering them and their families psychological support and help. A psychologist is actively involved in Glia's activities and organises support groups for patients and their families. Individual counselling on a weekly basis will be available by the end of this year.

Glia's psychologist also participates in writing psycho-educational articles, brochures and manuals for brain tumour patients. A patient manual, 'What to Do After a Brain Tumour Diagnosis', which deals with the psychological aspects of the illness and specific advice for patients and their loved ones in the Croatian language is the first such



**Above**: Glia Co-Founder and President Valerija Korent, a nurse in Zagreb, whose husband was diagnosed with a brain tumour

brain tumour patient information document to have received official approval in Croatia. It is delivered free of charge to patients and their families throughout many hospitals in Croatia.

Health workers should note that there is no universal psychological support approach for all patients. There are only common principles that say every patient must be treated as a dignified human being whose medical, social and psychological needs should be properly taken care of. In treating people who are struggling with life-threatening diseases it is necessary to put a heavy emphasis on social and psychological support. Communication between patients and health care professionals is the key to successful treatment and the achievement of a particular therapeutic target. Health professionals who work with cancer patients should show empathy and find time for the occasional extra word or two with their patients.

In Glia's support groups patients often



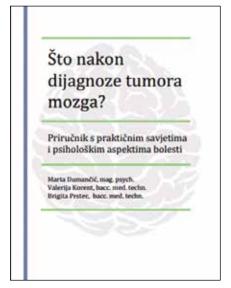
**Above**: Marta Dumančić, psychologist working with Glia

talk about problems and obstacles they have faced while communicating with health care professionals, especially doctors. They talk openly and honestly about what bothers them in that regard and what they would like to change. The sidebar with this article lists tips for health care professionals on how to communicate with patients and how to support them, based on Glia's members' experiences.

#### The importance of maintaining hope

Finally, never take away hope from patients. Do not talk to them about people who have died from the same illness or about pessimistic statistics regarding survival rates.

Remind them that every person and diagnosis is different and that cold numbers don't say anything about their situation. Give them hope, encourage them as much as possible and appropriate given the situation. Hope provides people with motivation, it gives encouragement and strength for further steps.



**Above**: The cover of Glia's patient manual 'What to Do After a Brain Tumour Diagnosis' in the Croatian language

When there is hope, patients can get up despite the pain and go to see their doctor or take part in some recommended physical activity. They can take an active role in their own treatment and get back a certain sense of control.

Glia, the Croatian Brain Tumour Patients' Association, has compiled this list of helpful tips for their health care professionals when they are communicating and supporting brain tumour patients. These are based on the real experience of Glia members during their brain tumour journey.

- Try to ensure a quiet and peaceful place where you can talk to your patients without being disturbed. Prepare for the talk, especially when you know there is not much time you are able to dedicate to that patient.
- Provide your patients with all necessary information clearly and gently. Make sure they understand the terms you use.
- Allow your patients to ask questions and try to answer them as clearly as possible. Encourage patients to write down your instructions and advice or do it yourself.
- In some situations it is okay just to remain quiet and present. It can be

- very helpful since it allows an overwhelmed person to clear their thoughts while feeling your support.
- Ask your patients how they feel. Do not automatically say that everything will be fine if you do not believe it.
- Do not force your patients to accept a particular treatment because you think it is the right path for them. Explain all the options clearly and give your opinion, but do not impose. Gently remind patients that they are the ones who make the final decisions about their treatment.
- Listen to your patients, encourage them to tell you their stories in their own words.
- Keep in mind that brain tumours affect the whole family. Talk with your patients about how their family and friends cope with their illness and think about the ways to include them in the treatment process.
- Gather relevant information about brain tumour patient/caregiver associations and support groups so you can recommend them to your patients.



## In Canada, every day 27 people are diagnosed with a brain tumour.

At Brain Tumour Foundation of Canada, you can:

- Connect with survivors and caregivers so you're not alone
- Attend learning events and find resources to better understand a brain tumour diagnosis
- Advocate to change practices and policies that are not inclusive of the brain tumour community
- Fund the best brain tumour research possible



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- 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 enquiry@braintumoursociety.org.sg

## **Cure Brain Cancer Foundation**

Making good headway on their mission to increase five-year survival from the current 20% to 50% by 2023

## Barrie Littlefield, Cure Brain Cancer Foundation

CURE Brain Cancer Foundation was established by Professor Charlie Teo AM in 2001. Charlie, a well-known and, at times, outspoken neurosurgeon, is also a strong patient advocate. He founded Cure Brain Cancer because surgery is never going to be a cure. It only buys patients time and, as important as that is, Charlie felt that there was not enough being done to find more effective treatments.

I first became involved in the Foundation as a parent/carer in 2011. My ten-year-old daughter, Eloise, had recently been diagnosed with a GBM and like many parents in this situation I was searching the world for answers – anything that might offer a little hope that she might beat the odds and survive, all systems intact. She was very keen to raise funds to help other little girls and boys in a similar situation so we participated in the Cure Brain Cancer annual Walk4BrainCancer. At that time there were just two walks in Sydney – now they are all over Australia.

Sadly, Eloise died in October 2011. Early in 2013, following a long period of reflection, I was invited to a two-day workshop with a difference! The two inspirational people behind this were the Foundation's Chair, Joanne Quin and CEO Catherine Stace. Charlie Teo set the tone for the workshop with this challenge: "Brain cancer survival has not changed in more than thirty years. How do we change it in ten?"

#### A challenging ten-year mission

The uniqueness of this workshop is hard to express in a few words. The format, setting, energy and creativity were palpable – everyone was committed and the quality of the people in the room, from all over



Above: Barrie Littlefield with his daughter, Eloise

the world and all walks of life, was very impressive. By getting representatives of the 'whole system' there, we were able to map it all out, identify the blocks and generate a plan.

Our mission emerged: to increase five-

year survival from the current 20% to 50% by 2023.

Like many parents, desperately wanting to hang on to the memory of their child, I flirted with the possibility of setting up my own foundation in Eloise's name, but in the end I felt that a better way to go was to join the team at Cure Brain Cancer Foundation. Having been part of the group that came up with the mission, I wanted to be part of making it happen. So, in mid-2013, I signed up.

Looking back at the last three years, it has been both one of the hardest and the most rewarding experiences I have had. I feel that I have used, to good effect, the knowledge I gained from many years of working in the corporate sector, much of it in pharmaceuticals, communications and change consulting.

Cure Brain Cancer is making good headway. But no doubt, many of you reading this may feel, I fear, that we are not

**Below**: Colleagues at Cure Brain Cancer Foundation in Australia





Above: Mapping out the GBM AGILE Trial

going fast enough. Every week, I get emails and phone calls from carers and people living with brain cancer, imploring me to help. Sadly and frustratingly, while some things have improved, there are still few treatment options available, and those that we have cause far too much damage. The much-respected, Distinguished Professor Web Cavenee, from the University of California, captured my feeling exactly when he spoke at our annual Gala Ball in 2014 and said: "The current situation is unacceptable."

## So what are we doing to achieve our mission?

We realised early on that it was pointless to carry on doing the same things that had been done for decades. The system hasn't worked for people with brain cancer, so we decided that we needed to take a disruptive approach – higher risk, but greater (and hopefully, quicker) rewards.

The Foundation's focus is research, advocacy and awareness. We champion collaboration, both in Australia and internationally, as it is by working together and eliminating siloed practices that we can get results faster. While we endeavor to act as a beacon for other brain cancer organisations in Australia, we are always mindful of our mission and 2023! Therefore, our collaborative model, which is very important to us as an effect-multiplier, is time-driven. We want to connect people and organisations and act as both host and glue. And, we have done

this very successfully with GBM AGILE – an important global initiative, led by Dr. Anna Barker.

We do not have time to sit in endless committees, coming up with consensus-based (and often mediocre) outcomes. We would rather take action, and if we fail, learn and move on quickly. Too many people are dying from this appalling disease and it has to stop. Time is of the essence.

We are helping to catalyse collaborative efforts across basic, translational and clinical research, with a key focus now on bringing world-class clinical trials to Australia, to give people here access to promising new treatments as soon as possible.

#### The Zero and GBM AGILE Trials

Two big bets were announced towards the end of last year, both innovative trial platforms to accelerate new treatments to patients – children and adults.





It is vitally important that both of these trials are funded quickly to get them recruiting patients as soon as possible. GBM AGILE is of particular importance, as this revolutionary, adaptive clinical trial platform, which will be rolled out at sites around the world, is set to change the way we do medical research.

While my biggest hope is that there will be a treatment breakthrough very soon, my biggest fear is that people who need it can't get speedy and equitable access to it. We are working hard in Australia to reduce the risk of this happening.

I am a passionate advocate for the rights of children and adults living with brain cancer. In my role as Head of Engagement, I am so lucky to meet many courageous people impacted by the disease. It is their will to get better, as well as the fighting spirit of Eloise, that drives me. I have no doubt that we will achieve our mission, collectively, collaboratively and with a smile.

For more information, please see Cure Brain Cancer Foundation: http://www.curebraincancer.org.au GBM AGILE: http://www. curebraincancer.org.au/page/173/ gbm-agile Zero: http://www.curebraincancer. org.au/page/166/zero-childhood-cancer

See Dr Anna Barker's article on the GBM AGILE Trial on page 13 of this magazine.



the challenges of brain tumours - plan an event for International Brain Tumour Awareness Week 2016 (22nd to 29th October)

## From cancer researcher to brain cancer patient: my 12 year journey with glioblastoma

## Yaron Sidney Butterfield Vancouver, Canada

IT is now 12 years since I was diagnosed with glioblastoma multiforme (GBM) brain cancer.

I was 29 years old, enjoying life, busy as can be, and my career was coming along nicely. I grew up in beautiful North Vancouver, British Columbia, Canada. I started my career in genomic sciences and my first highlight was playing a key role in our research centre as the first in the world to sequence and construct the SARS coronovirus genome. That was in the spring of 2003.

#### The day my life changed forever

Ten months later, on the morning of February 23, 2004, my life changed forever when I collapsed with a grand mal seizure. My world turned to silence and darkness while the rest of my family frantically dealt with paramedics, ambulance trips to the hospital, brain scans, and trying to figure out what was wrong.

The scans showed that there was something in my head. I slowly became self-aware a few days later at the hospital. It was a surreal time. I had a strong pain on my right side due to a tube stuck inside me to re-inflate my lung that had collapsed when the paramedics were treating me. I was convinced that was why I was in the hospital.

The following week, after the biopsy, we received the terrible diagnosis: Grade 4 astrocytoma or glioblastoma multiforme - GBM - which is a very serious form of brain cancer. I was told that although the prognosis was not good, there are some people who do survive a long time. I grabbed onto that tightly and never let go. I intended to be one of those long-term survivors.

Family, friends, colleagues near and far were all there for me, cheering me on and providing much support. Our hockey team was inspired and while in the hospital, the team was able to get to the divisional finals for the first time. After leaving the hospital



**Above**: Yaron Butterfield: cancer researcher, brain cancer survivor and artist

and before treatment, I was able to come out to the championship game that we won. It was an amazing evening.

The treatment plan set out for me by the wonderful team of the British Columbia Cancer Agency (BCCA) consisted of six weeks of combined temozolomide (TMZ) chemotherapy with radiation. The irony is that I was treated in the same building where I had been working as a cancer researcher.

I would create mental visualizations during treatment such as numerous x-wing fighters flying in my head focusing on blowing up the death star during radiation. Unfortunately, in the fourth week



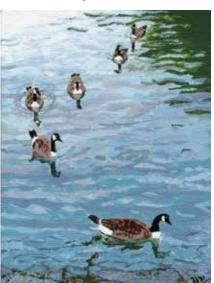
of treatment, I got grade 4 toxicity from the chemotherapy. I stayed over a couple nights in the hospital getting transfusions on the 5th floor of the BCCA. I recalled how a year before, I was working two floors below me, alone, until the early hours to put together the SARS genome. Now I was up late at the agency for a very different reason.

I finished treatment and continued living life. I started getting back in shape, ran a full marathon in Iceland, met someone and got engaged. Life was good and plans were in place to return to work.

#### Recurrence

However, in October, 2005, the MRI showed that the cancer grew back. My family and I were devastated. In the last few months of the year I took a drug as part of a clinical trial which failed miserably. The tumour had now doubled in size and therefore I was put back on TMZ. I remained positive and tried to stay

**Below left**: Untitled by Yaron Butterfield **Below**: Six Geese by Yaron Butterfield





Above: Yaron's colleagues, friends and family at the awards ceremony

healthy and strong. I knew the statistics for GBM when it comes back after initial treatment.

I took TMZ for the first week of each month beginning in January 2006. Those scary pills. I wondered if perhaps I couldn't complete the initial six weeks of chemotherapy because my body was just extremely sensitive to TMZ. Perhaps that was a good thing. As each month went by, it took me a little longer to recover and get my energy back. At the end of August, the MRI showed substantial reduction in the size of the tumour and each MRI since has not shown any changes.

Each time I was "promoted" to a longer period of time between MRIs I celebrated. Every three months, to every four and then every six months for quite a few years. I took advantage of my time off work to explore other endeavours I enjoy such as art. I took a course in acrylic painting which gave me feelings of accomplishment and made me realize that I can indeed learn new things. I read about neuroplasticity, which helped me realize that despite being bombarded with radiation and chemotherapy, the brain can continue to heal afterwards.

I returned to work which had changed drastically from when I left. The centre had moved to the short sequence read technology which led to a massive explosion of DNA sequencing.

#### A hopeful future

In 2008, our beautiful daughter Hana was born. My love for her makes me want to continue to do anything and everything I can to make sure the cancer doesn't come back

In 2012, I was lucky to have played a key part in the discovery of recurrent gene mutations in a type of brain cancer called oligodendroglioma. For more information on this see http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3246739/. That same year I volunteered to be part of the BCCA's Patient Navigator program which was a new initiative created by our Patient and Family Advisory Committee (PFAC) for brain cancer patients. Once or twice a month I meet newlydiagnosed patients with brain cancer. They have a chance to meet a long-term survivor of GBM which gives them much hope.

By 2014, I was having MRIs once a year. From my point of view, the cancer is gone and anything seen on the MRI is scar tissue.

One highlight in 2015 was the art show PFAC organized where we put out a call for artwork from anyone who was in the brain tumour community. We had a great response and during the week people were given the opportunities to learn of personal stories through art. You can see more about the art show here <a href="http://www.bccancer.bc.ca/library-site/Documents/Headlines\_2015\_Fall.pdf">http://www.bccancer.bc.ca/library-site/Documents/Headlines\_2015\_Fall.pdf</a>. There is also an article about the BCCA Art Show in this edition of *Brain Tumour* magazine.

I continue my work in cancer genomics and hope we can make further strides in brain tumour treatment.



**Above**: Marshmallows by Yaron Butterfield. Yaron is in red and his twin brother. Noam, is in blue

Don't miss an inspirational YouTube film about Yaron and his hockey team, the Sasquatch. See https://www.youtube.com/ watch?v=vVnzY0Lj5Ug Yaron also has his own website where you can see examples of his art. Please visit http://yaronart. weebly.com/





David Kelly Award presented to Yaron Butterfield

YARON BUTTERFIELD OF VANCOUVER was awarded the Brain Tumour Foundation of Canada's 2015 David Kelly Award for Community Service in a ceremony on September 24. This award honours an individual who exemplifies the spirit of community service to the brain tumour community and is named in honour of brain tumour advocate and fundraising leader David Kelly of Fredricton, New Brunswick, who passed away from a brain tumour ->

in 2014. http://www.braintumour.ca/5216/chairs-award

Yaron is truly deserving of this award as a tireless champion of brain tumour patients since his own diagnosis with a glioblastoma in 2004. He is a longstanding member of the brain tumour support group and is the co-chair of the Patient and Family Advisory Council (PFAC), an important committee composed of patients, family members and health care professionals that provides guidance to the BC Cancer Agency brain tumour care program. In addition, Yaron has undergone special training to serve as a "peer navigator," meeting with new patients to provide support and information. He has repeatedly served as a coordinator of the

annual Brain Tumour Foundation of Canada Spring Sprint, a fund-raising initiative to support our national brain tumour organization.

He also raises funds for the BC Cancer Agency through the Ride to Conquer Cancer. On top of all that, Yaron is a researcher at the BC Genome Science Centre where his work is aimed at discovering a cure for brain tumours. He is also a loving father to his beautiful daughter, Hana.

We are thrilled and proud to honour Yaron for his many accomplishments and his unstinting dedication to the brain tumour community.

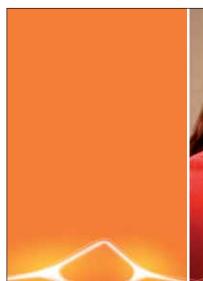
[Reprinted with kind permission of the BC Cancer Agency, Canada]

### BT5K

## Breakthrough for Brain Tumors Run & Walk



THE BT5K Breakthrough for Brain
Tumors Run & Walk is the American
Brain Tumor Association's annual,
signature fundraising event which
takes place in cities across the United
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participated, walking 25,011 miles
which were symbolically "donated" to
the IBTA's Walk Around the World for
Brain Tumours. See www.abta.org





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## The "Walk for Love, Walk for Hope" and "Happy Camp"

Two initiatives from the Childhood Brain Tumor Association (CBTA) in Taiwan

Ying-Hsiu Lin (林盈秀) Taiwan (R.O.C)











#### Walk for Love, Walk for Hope

The CBTA (Childhood Brain Tumor Association in Taiwan) held its Walk for Love, Walk for Hope in Taipei on November 29, 2015 for children with brain tumors. CBTA, established for 15 years since 2000, has become Taiwan's most important children's brain tumor care group. It exists to assist many families in facing the disease strongly and is the most important partner of Taiwan's major hospitals. Our walking activities enhance public awareness of brain tumors and the concerns arising from them.



Above: Happy campers at the Childhold Brain Tumor Association of Taiwan's event at the National Taiwan Science Education Center for patients and their siblings

#### **CBTA Happy Camp**

CBTA hosted Happy Camp on March 5, 2016 at the National Taiwan Science Education Center. Children with brain tumours and their siblings were invited to attend. The first part of the day was when campers made kaleidoscopes to observe beetles. The second part of the day was spent on making skin lotion and hand soap from fruit. Every child went home with a smile and a product at the end of the day's activities.

## A global web-based registry for rare pediatric brain tumours

CLINICIANS have long been challenged by the treatment of malignant childhood brain tumours.

Perhaps this is most true for rare childhood brain tumours. Many of these diseases are only seen three to four times a year even in the busiest of brain tumour centres in the world which deal with over one hundred children with brain tumours annually.

Clinicians are often challenged, not only by how to treat such patients, but also how to have reliable diagnostic tools to pick out such cases. These childhood brain tumours encompass a large category of tumours collectively called CNS-PNETs, rhabdoid brain tumours and others that remain to be identified

#### No clear diagnosis for some children

Dr Annie Huang at the Hospital for Sick Children (also known as "SickKids") in Toronto, Canada, started her interest in rare pediatric brain tumours as a fellow in training when she encountered patients for whom there appeared to be no clear diagnosis. She recalls looking up genetic studies of CNS-PNETs in 1999 and found that only 13 cases had been studied. So when she was embarking on her research and clinical career with the pediatric brain tumour program at the Arthur and Sonia Labatt Brain Tumour Research Center at SickKids, she focused on trying to advance research for these rare diseases.

With encouragement and support from her mentors, Drs Eric Bouffet and James Rutka, respective heads of the brain tumour clinical and research programs at SickKids, she started the painstaking process of building a bio-repository of rare pediatric brain tumours.

"It was a tedious but not a really difficult task at first as many doctors and researchers were quite happy to have someone who was interested in rare diseases and generously offered biological specimens that had been stored for many years but never studied," Dr Huang said.



Above: Dr Annie Huang

## An ever-growing repository of rare pediatric brain tumours

Thus over the course of the last decade and a half, Dr Huang's collection of rare pediatric brain tumours now numbers in the hundreds – collected from collaborators and colleagues around the globe. This rare tumours bio-repository enabled early studies and discovery of diagnostic markers for a poorly recognized brain tumour of infancy.

Dr Huang said that in their first study published in 2009, they identified the same genetic marker in a group of brain turnours that were called different names, and until that point were thought to be different diseases. Dr Huang points out that the discovery would not have been possible without international collaboration. She recalls that the initial discovery was based on analyses of eleven turnour specimens from nine different international centres, only one of which was from one of her patients at SickKids.

With the discovery of a diagnostic marker for these tumours - which is most commonly called ETANTRs but is also historically called by a number of different names - the disease is now increasingly recognized as a highly lethal form of brain

tumour in very young children.

## The global, web-based registry for rare pediatric brain tumours

Now investigators across the world are interested in establishing specific treatment trials for this disease, and are looking to data collected by the rare turnour network to see what type of treatment has worked for the survivors of this rare disease.

Dr Huang cites this as an example of why she and her colleagues felt it was time to launch a global web-based registry that will allow parents and clinicians from anywhere in the world to initiate the process of enrolling a child with a rare brain tumour diagnosis in this registry.

The registry website, which has been constructed with input and support from international clinical leaders in childhood brain tumours, will allow doctors to enter diagnostic, treatment and outcome information on their patients directly into a web-based database that will serve as a resource for future studies of other rare brain tumours not yet discovered.

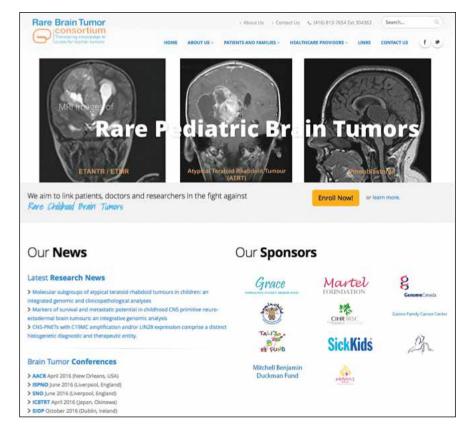
In addition, the registry encourages parents and clinicians to consider submission of tissue specimens for studies.

Dr Huang said: "Rare live tumour cells sent from different centres have been invaluable in our studies of new drugs in another rare tumour called ATRTs/rhabdoid tumours. Like the clinical database, I hope that the global bio-repository will serve as a valuable resource for studies of rare childhood brain tumours in many different countries."

#### A central hub for information and contacts

Another goal of the web-based registry is to centralize information and contacts for local experts so that parents can access reliable information and sources regarding such diseases.

"We often receive desperate phone calls or e-mails from parents from many different countries when their child is diagnosed with



Above: A screenshot from the Rare Brain Tumour Consortium's webpage

one of the rare brain tumours we study," Dr Huang said.

The web-based registry, she hopes, will also enable parents to seek help from more readily available local experts and be reassured that their child's management has been discussed and shared amongst the global experts in childhood brain tumours. Furthermore as the registry is tooled up with tweets and Facebook links, Dr Huang hopes it will also become an important source of support for parents and families of children diagnosed with rare brain tumours.

Dr Huang said: "Families who have lost children to these rare brain tumours have an unrelenting passion to help others and to seek answers. They are the major driver of our efforts. Without their grassroots financial support, our study of rare brain tumours would not have been possible, as such rare diseases do not generally attract much attention from large funding agencies."

Dr Huang also credits the tremendous enthusiasm and commitment of her colleagues across the world for the successful launch of this registry.



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## Breaking down barriers in children's brain tumour treatment

Emma Campbell<sup>1</sup>, Katie Martin<sup>2</sup> and Professor David Walker<sup>1</sup>

¹Children's Brain Tumour Research Centre, The University of Nottingham; www.cbtrc.org.uk

²Children with Cancer UK; www.childrenwithcancer.org.uk

With thanks to ecancer for producing and publishing the report on

Children with Cancer UK's Workshop on Drug Delivery in Paediatric Brain Tumours.

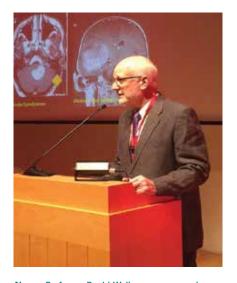
WORLDWIDE, 260,000 children develop cancer each year. Of these, between 30,000 and 40,000 have tumours of the central nervous system.

Treating children with any type of cancer poses a major challenge that doesn't apply to adult patients – the need to treat tumours in bodies that are still growing and developing. With children's brain tumours, the challenges ramp up. The brain is surrounded by a protective membrane called the blood brain barrier (BBB). Although this prevents toxins and infectious agents from getting into the brain, it also blocks most chemotherapy drugs.

On the 1st and 2nd February 2016, a pioneering scientific workshop dedicated to drug delivery in children's brain tumours was held in London, UK. This was initiated and funded by the charity Children with Cancer UK, and chaired by Professor David Walker from the Children's Brain Tumour Research Centre (CBTRC) at the University of Nottingham, UK. As well as UK scientists and clinicians, the workshop gathered leading figures from Europe, the United States and Canada, and also included other research funders, patient representatives, Home Office advisors and policy makers.

#### A selection of workshop highlights

"It doesn't matter how good the drug is – if you don't deliver it to the tumour, the treatment won't work," said Dr Kathy Warren from the US National Cancer Institute, and one of the keynote speakers at the workshop.



Above: Professor David Walker presents at the groundbreaking workshop on drug delivery in paediatric brain tumours

So, how can we deliver drugs to brain tumours, effectively crossing the BBB? Dr Jeffrey Penny (University of Manchester, UK) explained that molecules cannot pass the BBB if they are too large, have too high an electrical charge or if they are not soluble in fat. Some fat-soluble drugs can cross the BBB by diffusion, while other drugs may be actively pumped into cells by cell membrane 'transporters'. Other drugs disrupt or break down the BBB or block active transport mechanisms that pump drugs out of the cell. These can be used to increase uptake of the chemotherapy drug. Only by improving our ability to predict how the BBB will handle specific drugs, will we be able to refine and develop drugs that are more efficient at targeting brain tumours.



**Above**: Professor Henry Brem from Johns Hopkins University, United States was one of the keynote speakers

Professor Geoff Pilkington (University of Portsmouth, UK) added that the BBB is made up of many different types of cells, so a laboratory model of this complex system is needed to study drug transport through the BBB. Models developed by Professor Pilkington's team are proving very promising in that they appear to reflect the physiology of the BBB.

Drug delivery techniques that bypass the BBB have been in development for two decades. Professor Henry Brem (Johns Hopkins University, US) described the resistance he encountered on his pioneering work with Gliadel®. This is a biodegradeable polymer that is shaped like a wafer and impregnated with a chemotherapy drug called carmustine. The wafers are inserted into the brain cavity

that is created by surgical removal of the tumour, and slowly release the drug over time. Despite being told countless times that "it was a nice idea, but would never work", Professor Brem has shown that Gliadel®, in combination with radiation and the drug temozolomide, can extend survival, on average, for around a year and a half.

Dr Stuart Smith (University of Nottingham, UK) has used Gliadel® wafers to treat brain tumour patients. He suggested that the cavity wall could be lined with a drug-impregnated paste instead of wafers. This would be more mouldable and would better fit the shape of the cavity. Dr Smith and Dr Ruman Rahman (University of Nottingham, UK) are developing this paste - a biodegradeable compound of polymer (PLGA/PEG) microparticles mixed with multiple chemotherapy drugs. This is pasted around the cavity wall and ten minutes after exposure to body heat, the compound sets and drug release begins.

Another approach to get drugs into the brain is via intrathecal or intra-CSF (cerebro-spinal fluid) delivery. This involves injecting drugs directly into the cerebrospinal fluid. Professor Gudrun Fleischhack (Essen University Hospital, Germany) discussed how previous studies of intrathecal administration have shown the technique to be generally well tolerated but cautioned that, as yet, no drug possesses all the desirable attributes for this therapy. Professor David Walker (University of Nottingham, UK) described his work combining literature reviews with pharmacokinetic analysis to scrutinise existing drugs with potential for intrathecal administration. From an initial pool of 126 drugs, Professor Walker has identified 27 that are eligible for further investigation.

Dr Dannis van Vuurden (VU University Medical Centre, The Netherlands) presented an overview of another technique that bypasses the BBB – convection-enhanced delivery (CED). This involves the implantation of microcatheters, allowing the drug to be directly infused into brain tissues at a slow, consistent rate.

Professor Steven Gill (Bristol Royal Hospital for Children, UK) has developed a method of CED involving a unique implantable drug delivery system that permits repeated drug administration through four catheters fed by a skull-mounted transdermal port. Magnetic resonance imaging (MRI) and computerised tomography (CT) are used to plan positioning of the catheters, which are then delivered with robotic assistance. With approval for compassionate use, Professor Gill has treated several children with this system, controlling their tumours and extending their survival. A clinical trial

of Professor Gill's CED system will open to patients later in 2016.

### Shaping the future

Such was the dedication and passion of the delegates, that research collaborations suggested during the workshop have since been worked up into grant applications. Children with Cancer UK are as determined as the researchers not to let enthusiasm and momentum wane, and have opened a £1.2 million funding call to support projects related to the workshop. The charity has also invited an application from the Children's Brain Tumour Research Centre at the University of Nottingham to support the setting up of an international collaborative for treatment system development for children's brain tumours. Delegates from the UK, the Netherlands and the US have been in regular contact since the workshop to develop this framework. The time now seems ripe for pushing forwards developments in children's brain tumour research.

A more detailed workshop report and videos are available from ecancer: http://ecancer.org/ conference/articles/831-drugdelivery-in-paediatric-braintumours.php

## 19th Annual Race for Research (United States)

THE Southeastern Brain Tumor Foundation held its 16th Annual Race on 19
September 2015 in the neighbourhood of Atlantic Station, Atlanta, Georgia. More than 1,400 people were involved in the 5 km run and 2 km fun run/walk with participants being given the option of contributing their miles to the IBTA's Walk Around the World for Brain Tumours.

Starting early at 6.30am, 211
Southeastern Brain Tumor Foundation people took up the challenge, each averaging 5,086 steps; and by the time the sun had risen, they had proudly donated 536.5 miles.



## With a Little Help from My Friends

## Professor Terri Armstrong, PhD, ANP-BC, FAAN, FAANP Houston, Texas, United States

I grew up surrounded by family and strong role models of women working in healthcare in a small town in Ohio. When I was in college, the three most important women in my life (my mom, grandmother, and great-grandmother) were all diagnosed with cancer. This led me to seek out a position in oncology and over the years, I was able to be actively involved in their care. This experience taught me so much and led to the desire to do more to make the daily lives of people with cancer better.

After obtaining a Master's degree in oncology and a post-Master's as nurse practitioner, an opportunity to work with Dr Mark Gilbert, a well-known caring physician and a great mentor, became available and so my work with people with central nervous system tumors began. After several years, I realized that obtaining my PhD would be an important step to learn the skills I would need to try to find answers to solve the problems which central nervous system tumor patients were facing.

My focus since that time has been on patient-centered outcomes research, focusing on the impact of the trajectory of an illness, tolerance of therapy, and potential to influence survival. My work is never done in isolation, and I have been fortunate to work with teams of researchers, including those who work along with me, and important collaborators across different disciplines and across the world.

Central nervous system tumors are unique in that they represent both a neurologic and oncologic illness. As a consequence they often have a significant impact not only on the patient's function but on the family and community. Recently, studies to better define the disease have occurred, and improved understanding of the genesis of the disease and development of



**Above**: Terri and her daughter, Grace Armstrong. Grace will be studying at Barnard College of Columbia University in fall 2016

more effective therapies are on the horizon. The optimal approach must involve not only these developments but simultaneous understanding of the relationship to patient experienced symptoms and toxicity of these therapies and integration of the efforts to improve therapy and its impact on the individual patient.

My work is interconnected but I believe can be categorized into three general areas:

## (1) Improving assessment and our understanding of the experience of patients with central nervous system tumors

Patients with primary brain tumors are highly symptomatic, often from the time of diagnosis, with implications for functional status and making treatment decisions.

I led a team that developed the M.D. Anderson Symptom Inventory-Brain Tumor (MDASI-BT) and spinal cord tumors (MDASI-Spine).

We have done studies showing that symptoms are associated with tumor progression; quantify limitations of patient's



Above: The cancer diagnoses of three generations of women in Terri's family (greatgrandmother Bessie McFall, grandmother Genevieve Bovina and mother Donna Bovina Sanders) inspired her career path

functional status; that caregivers' reports are congruent with the patient and that electronic technology (such as iPads) can be used.



**Above**: Terri's team member Samuel Payen using electronic tablet technology for patient data

Our work with the Collaborative Ependymoma Research Organization (CERN, www.cern-foundation.org) has allowed us to reach out to patients with this rarer tumor to understand the natural history and impact of the disease and its treatment on patients across the world. Based on these surveys, we have developed materials to inform patients and are launching an expansion of this project in which we will evaluate risk factors (based both on history and genetics) for the occurrence of these tumors in adults and children.



Above: Weekly meeting with team members (left to right) Kristin Odom; Dr. Armstrong, Elizabeth Vera, Samuel Payen, Sonya Roberts, and Alvina Acquaye



**Above**: Elizabeth Vera (left) and Alvina Acquaye (right) working on the CERN survey

## (2) Incorporation of clinical outcomes assessment into brain tumor clinical trials

Although the impact of a brain tumour diagnosis on a patient's function and quality of life is well recognized, this impact had not been systematically evaluated in clinical trials or clinical practice. I have been fortunate to work with Dr. Mark Gilbert and Dr. Jeffrey Wefel to incorporate these outcomes into large clinical trials providing clear evidence that it is feasible to incorporate patient outcomes measures and that the results of these evaluations could impact on the interpretation of the clinical trial.

As a result of my involvement in these efforts, I recently chaired a day-long workshop exploring the use of clinical outcomes assessments (COAs) in brain



Above: Net Clinical Benefit collaborators Dr. Jeffrey Wefel (left), Dr. Terri Armstrong (center), and Dr. Mark Gilbert (right) after presentations on the Net Clinical Benefit portion of clinical trial RTOG 0825

tumor trials, a workshop co-sponsored by the FDA and the Jumpstarting Brain Tumor Drug Development (JSBTDD) consortia that also included members of the academic community, patient advocates, pharmaceutical industry and the National Institutes of Health (NIH). This successful workshop resulted in a series of white papers that were recently published on the importance of including COAs in clinical trials.

## (3) Identification of clinical and genomic predictors of toxicity

Toxicity associated with treatment also impacts the patient.

For example, temozolomide, the most common agent used in the treatment of brain tumors, has a low overall incidence of myelotoxicity (impact on blood counts that help to fight infection or clot the blood). However, in the select patients who develop toxicity, there are significant clinical implications (treatment holds or cessation, and even death).

I work with a group including Drs. Scheurer, Bondy, Gilbert, Sulman, Pugh, and Zhou that began to explore the clinical predictors of this toxicity and then explored associated genomic changes associated with risk. Currently, I am also working with a research team exploring risk factors and pathogenesis of radiation-induced fatigue and sleepiness, which is a major symptom in a large percentage of patients undergoing cranial radiotherapy for their brain tumor. The ultimate goal of this work is developing preventative or treatment measures.



Above: Toxicity Team members including (left to right) Alvina Acquaye, Dr. Melissa Bondy, Samuel Payen, Dr. Terri Armstrong, Dr. Michael Scheurer, Dr. Mark Gilbert, Dr. Renke Zhou, and Elizabeth Vera

In addition to conducting focused outcomes research, I have over 25 years' dedication to the clinical care of people with tumors of the central nervous system. This work is the best part of my job and is an inspiration and critical linkage to my research.

Recently, I was elected Vice President of the Society for Neuro-Oncology (SNO) so I am able to bring my perspective to an organization that recognizes the importance of all aspects of improving care.

In my free time, I enjoy being with my daughter Grace and caring for my rescue dachshund Diddy and a dorkie named Chachi.

## Kortney's Challenge



THE Kortney Rose Foundation held its 10th Annual Kortney's Challenge on 10 August 2015 to support paediatric brain tumor research. The event drew over 500 supporters to Monmouth Park, Oceanport, New Jersey. 528 miles were donated to the IBTA's Walk Around the World for Brain Tumours. Over \$64,000 was raised for the Children's Hospital of Philadelphia's paediatric brain tumor research consortium.

## Liquid biopsy of cerebrospinal fluid for less invasive and more effective characterization of brain tumors

Dr Joan Seoane, Director, Translational Research Program Vall d'Hebron Institute of Oncology (VHIO) Barcelona, Spain

ONE of the main challenges we face in our collective battle to combat cancer is tumor diversity.

Cancer is an extremely complex and heterogeneous, as well as fluctuating disease given that tumors are molecularly diverse and evolve with time. Moreover, tumors are formed by cells with multifarious states of proliferation, differentiation, motility (the ability of cells to move spontaneously and actively), and importantly, varying sensitivity to treatment.

In short, each patient has a unique tumor with a particular combination of genomic aberrations that can change during tumor progression. Our patients should therefore be treated with the optimal compound/combination of compounds to respond to the specificities of their respective disease. Since the selection of the most appropriate treatment depends on the specific molecular classification of the tumor in a given time, the challenge is to identify which therapy should be linked to which patient and in so doing, further advance precision medicine in oncology.

To date, the analysis of brain tumors has consisted of a biopsy or surgical sampling. Such approaches suppose risk per se and do not necessarily facilitate access to a representative part of the tumor. A new technique, liquid biopsy, has been recently and successfully developed which detects a tumor's specific mutations by means of the analysis of circulating tumor cell-free DNA.

The liquid biopsy 'policing' of cancer

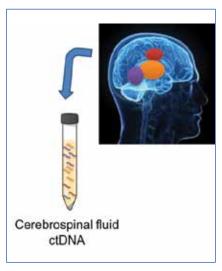


Above: Dr Joan Seoane

is not only facilitating a more precise treatment selection for each individual patient, but could also help us to be steps ahead of cancer's next move. Compared to traditional tissue biopsy, liquid biopsy is a much less invasive technique, and represents a significant forward step towards better detecting cancer mutations and tracking the evolution of disease, as well as predicting response to therapy.

Liquid biopsy in plasma has already proven useful across several tumor types but not in brain tumors. However, our group has discovered that the cerebrospinal fluid (CSF) is highly enriched with circulating tumor DNA and allows for the characterization of brain tumors.

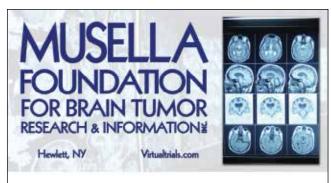
Cerebrospinal fluid flows through the brain parenchyma (the functional tissue in the brain) and the spinal cord and can be sampled by a lumbar puncture (similar to



Above: Genomic characterization of brain tumors through the analysis of circulating tumor cell-free DNA in the cerebrospinal fluid

an epidural puncture). Cerebrospinal fluid liquid biopsy opens a novel, pioneering line of research into biomarkers that enables us to monitor disease progression and ultimately help to evaluate the effect of treatment and drug action as the cancer progresses (see above illustration).

Raise awareness of the challenges of brain tumours - plan an event for International Brain Tumour Awareness Week 2016 (22nd to 29th October)



#### Patient Education and Support

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- NEW! Drug Discount Card Program!
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- Brain Tumor Virtual Trial
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#### Brain Tumor Research

- Funded over 40 brain turnor research projects
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## Keepin' On Keepin' On

## Matthew Fullerton Wichita, Kansas, United States

AT 17, I was told there was a malignant tumor in my right frontal lobe. Now - three decades later - I am a 28-year survivor of glioblastoma multiforme (GBM).

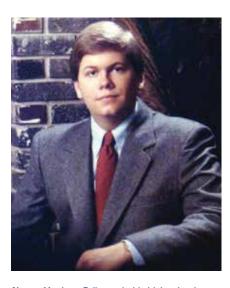
When I was diagnosed, a radiologist gave me the bleak prognosis of 90 to 180 days. I have now survived more than 10,000 days, when 100 days didn't seem possible.

I had surgery (gross total resection) and then the option of joining a brachytherapy clinical trial at UCSF (University of California, San Francisco) where they guided the placement of the I-125 radioactive seed implants. I was held in isolation for a few days until they removed the seeds. Fourteen months later, I returned for a craniotomy to remove the radio-necrosis caused by the brachytherapy because the trial had seen better survival results in those who had the necrosis removed.

When I was diagnosed in 1987, there was little information available about surviving GBM in the pre-Internet world. Ironically, I would soon become a support resource through my survival. Phone calls came pouring in from people desperate for hope and information in their own fight against GBM.

Since then, researchers have discovered the importance of each individual's genetic mutations. New radiation delivery tools like CyberKnife and X-Knife have been developed. Temozolomide together with radiation treatment, became the gold standard. Vaccines are being developed. Progress often seems to go at a snail's pace for those of us living with tumors, but these incremental improvements made in the last three decades are noteworthy.

During my remission, life returned to a certain degree of normalcy. Then six years post-diagnosis, a routine MRI discovered some recurrence and I returned to UCSF for another round of I-125 seed implants -



Above: Matthew Fullerton in his high school senior year photo - taken a month before his diagnosis of a glioblastoma multiforme

pushing my accumulated radiation therapy dosage to 170 Gy (Gy = "gray", a measure of absorbed radiation dose).

Almost a decade after diagnosis I began experiencing partial complex seizures and pursued temporal lobectomy surgery. The outcome was more manageable seizures and restored quality of life. Shortly after that, I began working as a programs director for an epilepsy support organization in Kansas in the United States. Today, advocating for people affected by brain tumors and epilepsy continues to be a driving passion for me.

When I was diagnosed, there was no one who offered hope.

We have advanced to the point that hope lives every day.

#### **SURVIVAL**

I believe a sense of humor is critical to survival. Humor conditions you to take the blows more gracefully. I found when I used humor with technicians and nurses it always put them more at ease. Humor keeps everything in balance.



**Above**: Matthew, during his second round of brachytherapy at UCSF

Finding support is crucial to survival. Local and on-line support groups are essential. There are several Facebook advocacy groups I use. It is also important to find a tumor-friend ("TF") who can be your rock in bad times and you can be there for them.

Those who have suffered the most have the most to give.

I met and became good friends with a fellow patient-survivor online - david m. bailey\* in Virginia. Diagnosed with a baseball-sized GBM in his prime (age 30), he gave up his corporate career and began a new life, picking up his Martin guitar and returning to his love of writing and performing music. During his 14-year fight he relentlessly toured the US and abroad and released 30 CDs (davidmbailey.com) while providing hope and inspiration to thousands of people across the globe. He generously allowed the International Brain Tumour Alliance (IBTA) to use his song "Keep On Walking" for the IBTA's Walk Around the World advocacy campaign.



Above: Matthew and david m bailey. David was also diagnosed with a glioblastoma and became a singer/songwriter whose music gave hope and inspiration to brain tumour patients around the globe Photo credit: Gray Matters Foundation

david was always composing music, sometimes scribbling lyrics on a napkin. I was with him at a conference in Houston when he was writing a new song called "One More Day" ("OMD"):

Don't let the grass grow beneath your busy feet,
Don't let the grass grow above you when you rest.
You've got one more day to get to where you're going,
One more day to give your very best.

He finished the lyrics and melody the night before the conference closed. He excitedly rushed to the stage to perform the song as his closing gift to attendees. This was the passion david had for sharing hope, and an affection for patients. He always took time to talk to his fans post-gig and many patients would share their life stories with him. "OMD" would become his keystone song for ending each performance.

david used to tell patient-survivors that he stopped asking "Why me" and changed the question to "What now?" - a much more productive and healthy question. He believed we all had a dream for a reason and was confident we all had the time to make it happen. In david's view, we brain tumor patients are the lucky ones in being given a chance to

really understand how precious life is and how fulfilling the moments in life can be.

david believed in sharing the message of hope. He said, "I think looking out to help other people is a great way to help your own heart." Most people think david's tumor killed him. I believe that his heart grew so large his chest could no longer contain it.

Much as other patients have told me that my journey inspires them, david was a beacon of hope that gave me strength and direction. He taught me how to "KOKO" ("Keep On Keepin' On" which was also the title of one of david's amazing



**Above**: Matthew believes a sense of humor is critical to survival.

songs). His GBM prognosis was as bleak as mine, and yet he was strong enough to have his six months turned into 14 years! David passed away in October 2010. I miss him every day.

When we consulted with my UCSF doctors prior to the brachytherapy, their concern was to save a 17-year-old. They warned that the massive radiation dosage would someday lead to deficits. Five years ago, I began to experience problems with my memory, multi-tasking and calendar management. All of these diminished to the point that I was unable to work. But no matter the challenge, I'm alive to face it head on, and isn't that really all that matters?

Told I wouldn't see my 18th birthday, 28 years later, I've had a good run. I believe that God is the only reason I have made it this far.

\* david m bailey always used lower case for his name.

## Astro Brain Tumour Fund Walk



ON Sunday 11 October 2015 over 418 people (and 171 dogs!) walked over 2,500 miles around the beautiful estate of Holkham Hall, Norfolk, raising over £8,000 for the Astro Brain Tumour Fund, a UK-based charity dedicated to low-grade glioma research and care. Routes of one, three, six and ten miles were organised so all ages and abilities could take part. Children also enjoyed a treasure hunt. After the event, walkers celebrated their success with a portion of fish and chips in Wells-Next-The-Sea.

For more information about the Astro Brain Tumour Fund, visit http://www. astrofund.org.uk ■

## Introducing Gris Positivo a new brain tumour patient and caregiver organization in El Salvador, Central America

### Gabriela de Hurtado San Salvador, El Salvador

GRIS Positivo (Gray Positive) is a non-profit, private organization founded in May, 2015 in El Salvador, Central America, by a small group of professionals concerned about making a difference for all stakeholders in the community of one specific condition: brain tumors. Our mission is to positively influence the process and outcome of patients in Central America through methods of education, awareness, advocacy, investigation and policy making.

Central America, with a total population of around 44 million, shares various similarities among its nations Belice, Guatemala, El Salvador, Honduras, Nicaragua, Costa Rica and Panama.

- •They are low-middle income countries with limited access to healthcare.
- They have precarious/outdated public supplies of health services (including oncology and radiotherapy treatments).
- Generally, the populations are only educated to a low overall level.
- They have low public investment in preventive and curative health (expense in health as a percentage of GDP).
- Registries of health indicators are poor
   especially, though not limited to, cancer and brain pathology cases.

One particular thing that shocked and motivated us the most was the repeated and irresponsible tendency in which patients diagnosed with any type of brain tumor were discharged from health facilities with a catastrophic prognosis and with a terminally ill "there is nothing left for you to do" label.

As would be expected, this label (words from the doctor, the person a patient is most likely to trust and believe) dramatically destroyed patients' and families' hope, ability to cope, and - worst yet - motivation to fight.

Gris Positivo adopted, as a strategic



purpose, a firm commitment to not only make our public aware of brain tumors as a real condition that might affect anyone at any time but also to discuss treatment options, medical and technological advances and other relevant measures that undoubtedly add value to a patients' prognosis and quality of life.

At Gris Positivo, we channel our resources toward five actions that we consider to be crucial:

- education in health as an empowering tool for patients, their families and caregivers;
- guidance in seeking second medical



Above: Gabriela de Hurtado, co-founder of Gris Positivo

opinions and finding updated therapeutic approaches and alternatives to specific conditions;

- emotional support;
- access to valuable information for all stakeholders;
- data registry and analysis, investigation,



policy making, and project proposals to enhance the region's response capabilities around this condition.

Throughout our first year, we have been honored with the invaluable collaboration and input of various supporters. An example of this is Fundación Edificando Vidas (FEV), a local NGO founded by our dear friend Marcella Carrillo, an ovarian cancer survivor who has devoted her life to the cause of cancer and has become our Salvadoran strategic partner. FEV has trained our star team of brain tumor patient survivors - whom we address as our "Faces of Hope" - to become patient advocates through guided emotional and spiritual support. Along with FEV, we have held various awareness and educational events such as trainings, galas, talks about specific conditions and topics, fun activities and others.

Our "Faces of Hope" have supported numerous patients after diagnosis, throughout treatment and upon loss. Local and international oncologists, neurosurgeons, psychologists, communicators, administrators, many other professionals and anonymous individuals have selflessly donated cash, in-kind benefits, talent and expertise to our cause. Their generosity is the source of countless blessings to our young organization.

On the eve of celebrating our first anniversary, we are grateful, hopeful and looking forward to all that is yet to come!





### Brain Tumour Ireland



BRAIN Tumour Ireland's annual 10K & 5K Run Fundraiser took place on Sunday, 1 November 2015, at Corkagh Park, Dublin. Clear blue skies greeted the runners and walkers as they set out on a 10 km or 5 km route. Participants could either take part in a timed race or untimed walk.

A total of 1,085 km was 'donated'

to the Walk Around the World for Brain Tumours and €3,285 was raised. Brain Tumour Ireland will use these funds to provide crucial support for brain tumour patients in Ireland, of whom there are approximately 400-500 newly diagnosed in the country each year.

Visit Brain Tumour Ireland's website at http://www.braintumourireland.com/bti/

### The gift of hope



In January, 2016, the Philippines
Brain Tumor Alliance (PBTA), the Bible
Institute for the Deaf (BID) and culinary
students visited pediatric and adult
charity wards at the Philippine General
Hospital to distribute items from the
Convoy of Hope. Special thanks go
to Dr Gap Legaspi, Dr Marilyn Hong,
Rev Raul Manuel and Miss Candice
Colleen Manuel.





Report of the
Second World
Summit of
Brain Tumour
Patient
Advocates

By Dr Stuart Farrimond

International Brain Tumour Alliance (IBTA)

We are pleased to include in this edition of Brain Tumour magazine excerpts from the IBTA's Report of the Second World Summit of Brain Tumour Patient Advocates. The full report is available here: https://issuu.com/ibta-org/docs/ibta\_summit\_report\_2015

For a hard copy of the Summit report, please contact chair@theibta.org

Sitges, near Barcelona, Spain 25 - 27 October 2015

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### **Acknowledgements**

The International Brain Tumour Alliance is grateful to the following companies for their support of the Second World Summit of Brain Tumour Patient Advocates.

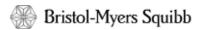


























#### In addition...

We are very appreciative of the wise advice, help and support provided by the IBTA's 14 Senior Advisors on this project: Jean Arzbaecher, Jenny Baker, Rosemary Cashman, Maureen Daniels, Stuart Farrimond, Jennifer Gouchie-Terris, Carol Knight, Carol Kruchko, Sharon Lamb, Mary Lovely, Mary Ellen Maher, Gordon Oliver, Sally Payne and Chris Tse.

A big thank-you to our medical specialist participants who made time in their hectic work schedules to join us in Sitges and to generously impart their knowledge: Professor Garth Cruickshank, Dr Joan Seoane, Professor Roger Stupp and Professor Martin Taphoorn.

Grateful thanks go to Ms Christine Quah, Manager, Global Accounts, HelmsBriscoe (www.helmsbriscoe.com) for her invaluable help in finding and securing our Summit venue.

Many thanks also to the Melia Sitges Hotel, Sitges, Spain, for their patient and always-efficient help with our accommodation and conference arrangements.

The Second World Summit of Brain Tumour Patient Advocates, a project of the International Brain Tumour Alliance (IBTA), is a wholly independent activity and has been conceived, planned and carried out by the IBTA. For details of the IBTA's sponsorship and transparency policies, please see www.theibta.org

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# Report of the Second World Summit of Brain Tumour Patient Advocates Executive Summary

Sitges, near Barcelona, Spain 25th, 26th and 27th October 2015

### The Main Findings

THE main findings from the Second World Summit of Brain Tumour Patient Advocates were that:

- Brain tumours spell "challenge" in any language.
- One of the biggest and most significant hurdles facing brain tumour patients today is equitable access to the latest therapies.
- International support, encouragement and involvement is urgently needed for brain tumour organisations working in developing countries, such as Cameroon, Zimbabwe, South Africa, The Philippines and India
- The care, support and treatment of pediatric brain tumour patients pose their own specific challenges. As was clear at the Summit, in many parts of the world facilities and services for this age group are significantly sub-optimal. Stories recounted in the pediatric session were particularly moving and all of these presentations were rated very highly for impact and relevance by Summit attendees on their feedback forms.
- There needs to be a much greater focus on quality of life (QOL) issues for brain tumour patients, both in the clinical and the research setting. Better tools need to be developed to measure QOL, perhaps making increased use of advances in digital technology and communications.

- Differences in cultural beliefs and perspectives need to be better understood and appreciated as they may influence approaches to brain tumour patient support and care.
- The panel discussion session "Research and Development for Brain Tumour Treatments – Thinking Outside the Box" included a diverse group of stakeholders: a caregiver to an adult patient, a representative of a pediatric not-for-profit brain tumour organisation, a medical professional, a brain tumour researcher and a representative of the pharmaceutical industry. This session was particularly highly-rated by Summit participants for its impact and relevance, demonstrating the value and importance of involving all stakeholders in decisions and actions relating to the treatment and care of brain tumour patients.
- It is crucial for brain tumour patient advocates/leaders from non-profits and charities around the world to have the opportunity to meet regularly together to discuss their challenges, solutions, opportunities and accomplishments.
- OVERALL, the Second World Summit of Brain Tumour Patient Advocates was highly rated on feedback forms as being "very valuable", "very relevant" and "very well organised".

With more than 70 participants from 27 countries, the Second World Summit of Brain Tumour Patient Advocates took place from 25th to 27th October 2015 in Sitges, near Barcelona, Spain.

The conference was an unequivocal success and provided a unique opportunity for patient advocates to share information, exchange best practice and discuss and debate some of the pressing topics in the field of brain tumours today. Attendees renewed acquaintances from the First World Summit (in 2013) and forged friendships with newcomers who attended the Summit in Stiges for the first time.

In addition to patient advocates (some of whom were patients or caregivers/ former caregivers), the Summit participants included a number of medical and research professionals, and representatives of the pharmaceutical industry. The presence of a diverse group of stakeholders at the Summit ensured that there was an educational, collaborative and transparent focus on some of the biggest issues facing the international brain tumour community today.

To this end, the main topics discussed were:

the latest and most promising brain tumour therapies, encompassing neurooncological, surgical and supportive care approachesquality of life issues and measures and how they are perceived in various regions of the world

- brain tumour case studies in the context of country-specific settings (specifically Cameroon, France, Croatia, India and Turkey)
- healthcare systems and regional



challenges, including access to therapies, support and information

- The Brain Tumour Patients' Charter of Rights (2010) and its relevance to stakeholders today
- 'thinking outside of the box' regarding research and development for brain tumour treatments
- pediatric brain tumours: sharing experiences from the United States, Japan, South Africa, Italy and Spain

All of these sessions and discussion groups saw hearty debate, leading to a greater understanding among the Summit participants of the various perspectives in the international brain tumour community. The stories, opinions and discussions shared at the Summit emphasised the crucial importance of everyone – patients, caregivers, advocates, medical professionals, academia and industry – working together to improve areas of unmet need in the neuro-oncology field.

Each attendee also had the opportunity to attend four practical workshops of their choice over the two days of the Summit. These provided informal and interactive opportunities to share skills and knowledge, and develop new competencies. Summaries of the workshops are included in this report.

In addition to the business of the packed two-day programme, participants also had time for some valuable networking with one another during breaks and meals at the Summit hotel.



Above: Participants at the IBTA 2015 Summit in Sitges, Spain, represented 27 countries:

Australia 
Belgium 
Bulgaria 
Cameroon 
Canada 
Croatia 
Cyprus 
Denmark 
France 
Germany 
India 
Ireland 
Italy 
Japan 
Lithuania 
Netherlands

New Zealand 
Philippines 
Singapore 
South Africa 
Spain 
Sweden 
Switzerland 
Turkey 
United Kingdom 
United States 
Zimbabwe



### **Introductory Presentations**

### Be the change

Markus Wartenberg (Germany) officially opened the IBTA Summit, warmly welcoming the over 70 delegates from 27 countries.

As the facilitator for the first World Summit of Brain Tumour Patient Advocates in 2013 in Lafayette, California, USA, Markus celebrated the growth of the IBTA community, greeting faces new and old. Markus is the Honorary Senior Manager of the charitable patient advocacy organisation Das Lebenshaus e.V. (The House of Life) and he spoke of the shared challenges faced by rare cancer communities around the world and the ever-present need to work together across geographic borders.



Markus set the scene for the Summit, passionately stressing that a patient group's role could be summarised in the single word "change". Patient groups exist not only to support patients and their families but to "be the change," he said. The Summit's aims were for delegates to learn from each other and share their experiences, while not trying to convince each other that there is a 'right way' to perform patient advocacy.

Markus explained that the advocates present collectively represented over 600 years of experience and with so many cultures also represented, the conference was set to be a mutually empowering event that would help equip both small and large organisations in their missions. Solidarity, sustainability and engagement were overarching themes of the Summit, while curiosity and having fun were "strongly encouraged"!



Markus Wartenberg, a leading European cancer patient advocate, was the professional facilitator at the IBTA Summit.





Markus introduced two 'graffiti boards', positioned at either side of the main meeting room. One was a blank canvas for delegates to write ideas, post messages or state challenges and solutions which they wanted to share with fellow Summit participants. The other was a space for 'wants' and needs. By participants posting a "want" it was hoped that others at the Summit could help provide whatever was being sought, for example, awareness material, advice, etc.



A "wanted" board was available at the Summit for participants to leave a "classified advertisement" on a Postit Note for others to see with requests for support materials and advice.



#### Welcome address

Kathy Oliver, Co-Founder and Co-Director of the IBTA, then welcomed all delegates, explaining that the Summit dates were chosen to coincide with the beginning of the International Brain Tumour Awareness Week, an annual awareness-raising initiative coordinated by the IBTA. Being together at this milestone occasion reflected the solidarity of the IBTA vision, she said.

"...there are are no vast oceans or long distances that can keep us apart when we share the same goals."

Kathy explained the mission and activities of the IBTA, which include:

- advocating 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.
- facilitating collaboration within the global brain tumour community
- providing a strong and collective voice for brain tumour patient organisations across the world

She added that the Summit was a unique opportunity to share experiences, be refreshed, and enjoy being in a different environment. She also thanked the industry sponsors for supporting the Summit.

Kathy hoped that the two days of the Summit would foster a greater sense of camaraderie among the delegates, a greater understanding of cultural and regional differences and similarities, and increased appreciation of the challenges faced by the different patient groups represented at the meeting.



IBTA Chair and Co-Director Kathy Oliver delivering the Summit welcome address



Over 70 people from 27 countries attended the IBTA Summit.



"We are the United Nations of brain tumour patient advocates," Kathy Oliver said.

Looking back at the growth of the IBTA since its inception on 7th May 2005 in Edinburgh, UK, Kathy reflected on the achievements, sacrifices, and courage shown by members of the brain tumour community that she had witnessed over the past decade.

"In my ten years with the IBTA," she said, "I have learned a lot about people, about life, and sometimes about death. But there have been many very, very positive and hopeful things that I have come across in this world of brain tumours. And the

determination and positivity which drives everyone in this field never ceases to amaze me."

She added that the global reach of the IBTA could be likened to "the United Nations of brain tumour patient advocates".

She summarised by saying: "This Summit, and all it stands for, is proof to me that there are no vast oceans or long distances that can keep us apart when we share the same goals."



### Keynote Presentation - Professor Roger Stupp (Switzerland)

### An Overview of Current Brain Tumour Practice and New Advances in Brain Tumour Treatments

#### **Key points:**

- Brain tumours are 'rare' and there is often little or no data about them.
- Tumour grading is not absolute and should be seen as a 'continuum'.
- Contrary to conventional wisdom, 'high grade' glioma patients fare best when treated early with a combination of therapies.
- An important aspect for patients is to seek care from specialist centres; patient advocates can encourage and support this.
- For some low grade glioma patients, less treatment is more.
- Patient advocates can help the international brain tumour community by calling for tumour tissue and patient data to be shared for research purposes.
- Tumour Treating Fields' technology is an entirely new treatment modality.

ROGER Stupp, Professor and Chairman of the Department of Oncology and Cancer Centre, University of Zurich and University Hospital Zurich, is an award-winning and widely-esteemed doctor and researcher in neuro-oncology. His keynote speech offered an overview of present and potential brain tumour treatments, addressing topics ranging from chemotherapy and radiotherapy regimens, to molecular markers and 'Tumour Treating Fields' therapy.

Prof Stupp explained that brain tumours represent a particular challenge in the search for new treatments. Brain tumours make up only 2% of all cancers and, given their rarity, there has been little interest historically in investing in research. Hence, there is often little or no data available upon which treatment decisions can be made, he said. The advent of temozolomide over a decade ago - the result of a combined international effort - was a watershed moment in brain tumour therapy.

Prof Stupp's presentation focused primarily



Professor Roger Stupp presented an overview of current brain tumour practice and treatments

on glioma research. He explained that gliomas are thought to arise from the structural tissue around neurons and are usually categorised into distinct grades (I, II, III, IV).

However, it is more useful to consider tumours as existing on a spectrum of aggressiveness rather than assign them to exact categories, he said. Tumour grades are used to determine treatment decisions, although these guidelines ought not to be considered 'law', as they do not reflect the reality of tumours being on a continuum.

"High grade glioma patients should be treated early and with a combination of chemotherapy and radiotherapy."

Looking back over the history of glioma treatment, Prof Stupp stated that as recently as 1995 surgery and radiotherapy were the only available treatments. In the year 2000, temozolomide (Temodal®, Temodar®) chemotherapy was introduced, although initially

only as a last resort. Brain tumour research had focused on patients "no one wanted to touch" and for whom all other options had failed.

He presented data from research published in 2005 (in the *New England Journal of Medicine*) that showed that chemotherapy (temozolomide), when given in combination with radiotherapy, was effective in reducing turnour growth and extending life. A key lesson from that research and similar studies over the past decade, he said, was that high grade glioma (glioblastoma) patients should be treated early and with a combination of chemotherapy and radiotherapy. He stressed that there is a pressing need to change existing paradigms and to offer treatments early, thereby "giving the patient a better chance".

Prof Stupp said that a crucial role for patient advocates is to support patients in finding the best specialist centre to receive treatment. Recounting the story of a brain turnour patient referred to him for a 'relapse', he discovered that the patient's new neurological symptoms were actually due to medication side effects. It is therefore important to seek care in a specialist centre where doctors are very experienced in brain turnour care, he said.

Prof Stupp also discussed the variation between nations over how readily patients are referred to specialist brain tumour centres. Therefore it is imperative for advocates in all countries to help patients seek out professionals with expertise.

"A crucial role for patient advocates is to support patients in finding the best specialist centre to receive treatment."

Prof Stupp added that low grade gliomas present particular challenges when deciding



on treatment because there is a high variability in outcome. Approximately 50% of patients are progression-free for three to five years, and 50% are alive for seven years or more. He said that for some patients, less treatment is more.

A trial published in the *Lancet* in 2005 showed that among low grade glioma patients, there was no great benefit from early radiation therapy. A significant proportion of those who received radiotherapy in the trial received no benefit whatsoever. Conversely, data for high grade glioma shows that the opposite is true. Despite considerable variability in outcome, more aggressive treatment of these patients is usually beneficial, he explained.

When considering the development of new treatments, understanding the biology of tumours is key, Prof Stupp said. He added that it is getting increasingly difficult to share individual patient data and tissue samples for research purposes, due to rules and legislation designed to protect privacy. In this area patient advocates can aid research progress by challenging pathologists and legislators for data to be shared, as well as urging that large archives of tissue samples and data be established.

"We need facts, we need science."

Despite these hurdles, some research progress has been made through shared

tumour data, Prof Stupp said. Using nearly 1,000 matched tumour and patient blood samples from the Duke University Biobank in North Carolina (USA), the IDH mutations were discovered in 2009 and these mutations have significant implications for glioma progression and tumour behaviour.

This and other data-based research has led to the emergence of tumour classifications based on molecular markers, which promise to better inform future treatment and offer new avenues for chemotherapy development. Specifically, MGMT methylation status in a glioblastoma is the strongest predictive (how to treat) marker and indicates whether chemotherapy with alkylating agents (i.e. temozolomide) will be effective. Using research data, Prof Stupp explained that for unmethylated glioblastoma tumours there are presently no good alternatives to temozolomide and in this unmethlyated patient group chemotherapy has only marginal effect.

He stressed the pressing need for further research and, in particular, for clinical trials of new and potentially better chemotherapy agents for patients with unmethylated glioblastoma tumours. Patient advocates can be influential in how research progresses, Prof Stupp stated. "There is a need to come together to get the work done," he said. "It will make a difference – we need facts, we need science."

Therapies targeting tumours with IDH mutations, for example, are presently under investigation, and Prof Stupp hopes these therapies will be effective. He went on to offer a brief overview of the many genetic



IBTA Chair Kathy Oliver presents Prof Roger Stupp with a memento of his participation at the Summit.

variations that are now known to exist in astrocytoma and oligodendroglioma tumours, although many of these currently have no determined clinical significance yet.

Looking to the future, Prof Stupp discussed the role that 'Tumour Treating Fields' therapy (TTFields) may have in brain tumour treatment. He presented the latest clinical trial data and explained the rationale behind the therapy: rapidly alternating electrical fields disturb cancer cells' ability to divide, which ultimately causes the rapidly dividing cancerous cells to undergo 'programmed cell death' (apoptosis).

The data for the NovoTTF-100A portable device (now named 'Optune') showed benefit to glioblastoma patients when combined with temozolomide, with minimal toxicity and side effects. Skin irritation where electrodes are applied to the scalp was one of the most common side effects.

Prof Stupp concluded his presentation by taking questions from the floor.

Several delegates questioned the robustness of the TTFields data, asking whether the data showed a true benefit. Prof Stupp affirmed that the data was robust and could not be explained by the placebo effect.



Lia Le Roy (Werkgroep Hersentumoren in Belgium) asked how patients can weigh up the benefits versus the risks of a clinical trial. Prof Stupp discussed

the balancing act faced by physicians too, namely that if people are given masses of information, perhaps it might be difficult to weigh it all up and come to a reasonable decision.







### Keynote Presentation - Professor Martin Taphoorn (The Netherlands)

### Quality of Life in Brain Tumour Patients

### Key points:

- Malignant brain tumours are unique among cancers and are 'two diseases': a progressive neurological disease and a malignancy currently without cure.
- Treatments can improve quality of life and patients will adapt to their new situation (termed "response shift").
- There is often a 'trade-off' between quality and quantity of life, although the effects of individual treatments are very varied.
- There is a need for clinical research to measure health-related quality of life, not just survival.
- The role and challenges of caregivers also need to be considered.

MARTIN Taphoorn, MD, PhD, is a neurologist and professor in neuro-oncology at Leiden University Medical Center and at the Medical Center Haaglanden, The Hague in The Netherlands. He is a leading authority on quality of life issues in brain tumour patients. His presentation focused on how quality of life may be measured in clinical brain tumour research, and the role patient advocates can play.

Brain tumours have unique quality of life issues not seen in other conditions, Prof Taphoorn said. Likening brain tumours to two separate diseases, he said that a malignant brain tumour is both an 'incurable cancer' and a 'progressive neurological disease'. He used two case studies to highlight quality of life issues that can occur with brain tumours.

"Brain tumours have unique quality of life issues not seen in other conditions."



Professor Martin Taphoorn gave a fascinating presentation on quality of life for brain tumour patients.

The first case study was of a 49-yearold man, who experienced seizures and progressive dysphasia (difficulty speaking) in 2010. Diagnosed with a glioblastoma tumour, he received surgical resection, and radiation therapy together with temozolomide chemotherapy (the 'Stupp regimen'). Five years later, he was clinically stable, without seizures, requiring no regular medication and was able to work part-time while pursuing his hobbies.

The second case study was a woman aged 46 with a low grade oligodendroglioma in the right temporal region but who was otherwise well. Diagnosed in 2001 following seizures, she initially received radiation therapy and then returned to work. In 2004, she suffered further seizures and a loss of functioning in her right arm. The tumour had regrown and had developed into an anaplastic oligodendroglioma. She underwent surgery and received PCV chemotherapy.

"It was a success story... she did well for a couple of years," Prof Taphoorn said, but then she slowly deteriorated. In 2008, she had cognitive deficits (as a result of both the disease and the treatment) and had become wheelchair-bound. She was unable to work as a teacher or manage her family responsibilities. Receiving care in a nursing home, she experienced "reasonable quality of life" but died of pneumonia one year later.

"We need to do more than work out how to prolong brain tumour patients' lives."

Prof Taphoorn explained that from these two case studies there are several lessons to be learned. The second case study showed that a relatively benign tumour can become aggressive, resulting in complications and deficits due to both the tumour and the treatment. He said that it is often assumed that health-related quality of life always deteriorates over time but this is not necessarily true. Treatment can lead to improvements in quality of life, he said, and the increasing survivorship among brain tumour patients is further challenging longheld assumptions about outcome.

He explained that as quality of life changes, patients will adapt to their situation ("response shift"). Prof Taphoorn emphasised that patients often say that they have a good quality of life and it is important to always ask patients about their quality of life rather than make assumptions.

Prof Taphoom highlighted that health-related quality of life (HRQoL) is inherently subjective when it is measured. We need to be aware that cognitive impairments may affect a person's assessment of their quality of life, he said.

Prof Taphoorn went on to discuss the many factors that influence a brain tumour patient's quality of life, considering the effects of both the tumour and the treatments. He stressed that there is a need for research



to include 'clinical outcome assessments' (i.e. HRQoL measurements) rather than only focusing on 'traditional outcome measures' such as overall survival, progression free survival, and MRI results.

From a clinician's perspective, this presents many challenges. "Before I can ask a patient how they are doing, they are asking me 'how is the scan?'" Prof Taphoorn said. HRQoL assessment includes psychological, physical, social and symptom factors. They are not easy to aggregate into one overall score (unlike survival figures), but these factors still have value in clinical practice, he said. HRQoL assessment facilitates both decision-making and communication between doctor and patient.

Prof Taphoorn explained that a variety of validated tools and questionnaires exist for measuring quality of life, such as the EORTC (European Organisation for Research and Treatment of Cancer) questionnaire QLQ-C30; the Functional Assessment of Cancer Therapy (FACT-G); and the MD Anderson Symptom Inventory (MDASI).

### "We should not forget the impact on the caregiver."

Referring to published data, Prof Taphoom stated that there is often a 'trade off' between quantity and quality of life,



Data on quality of life for brain tumour patients is currently limited, said Professor Martin Taphoorn at the IBTA Summit.

whereby treatments often negatively affect quality of life, especially those given at higher doses, while prolonging life. Data shows that living with a brain tumour lowers HRQoL but the effect "is not as large as one might assume," Prof Taphoom said, thanks to individuals' ability to compensate.

"We should not forget the impact on the caregiver," said Prof Taphoorn, before showing data that indicated that the mental health of caregivers for high grade glioma patients is significantly worse than for those who care for low grade glioma patients, or who are not caregivers.

Health-related quality of life invariably declines in the end-of-life period, Prof Taphoom explained, a finding that is consistent across several European countries. Most patients say they would prefer to die in their own home. In the Netherlands, dying at home is the norm, while in Austria death most often takes place in hospital and in Scotland it is in a hospice. Yet despite these differences in place of death, Prof Taphoorn showed that perceived quality of care in these countries is broadly similar.

Prof Taphoorn concluded that data on quality of life in brain tumour patients is currently limited but should serve as a starting point in our mission to try to achieve measurable quality of life improvements in these people. He said that doctors might presume that questionnaires are a burden to patients – when in reality they often are not. Because of various other issues, compliance and survey completion rates remain low, and data for individual patients is often missing.

Prof Taphoom emphasised that there is a pressing need to find out what the net clinical benefit of any intervention or treatment is – and this includes measuring both survival and quality of life.

Below: Prof Martin Taphoorn spoke at the Summit about the many factors which can influence a patient's quality of life.



<sup>1</sup>Health Related Quality of Life (HRQoL) refers to the measured physical, functional, social and emotional well-being of an individual. Quality of Life (QoL) is a patient's overall assessment of their well-being.



### Keynote presentation - Prof Garth Cruickshank (United Kingdom)

### **Neurosurgical Approaches to Brain Tumour Treatment**

### Key points:

- Symptom improvement is one of the "most useful outcomes" of brain tumour surgery.
- Brain tumours can grow in size and invade/spread into tissues. Surgery focuses on treating a tumour's local growth.
- Brain tumours damage connection pathways within the brain; increased scientific understanding of these pathways will help minimise surgical risks.
- Individualising therapy is a major challenge: low grade gliomas invariably grow but genetic profiling now shows that some 'low grade' tumours are highly aggressive.
- High grade glioma patients fare better with aggressive treatment.
- Elderly patients should receive active treatment, providing their functioning is preserved.
- To improve brain tumour treatments, tumour tissue samples are needed.
- Obtaining consent for surgery involves exploring a person's lifestyle, priorities and concerns - not merely explaining risks.

GARTH Cruickshank, Professor and Consultant Neurosurgeon at the University of Birmingham and Queen Elizabeth Hospital in the UK, has for many years been at the forefront of clinical research in surgical brain tumour care. He is a university lecturer and teacher, and serves in an advisory role in the UK National Health Service, where he works to improve outcomes for brain tumour patents.

In his keynote presentation at the Summit he provided an overview of current and future surgical approaches, the rationale behind them, and the potential impact each intervention may have on the patient.

Prof Cruickshank gave a brief description

of the different locations within the brain where tumours commonly occur, highlighting the varied symptoms that they can produce as a result, and the complex clinical challenges that they pose to surgeons. He explained that as our knowledge of communication channels within the brain has increased, we can better understand that it is both a tumour's location and the connections it affects that cause symptoms. Further advancements in our understanding of these connections will also help surgeons know how to operate more safely, he said.

Glioma surgery forms the bulk of a neurosurgeon's work, Prof Cruickshank explained, with metastatic brain tumours becoming increasingly important. He said that few people realise that brain tumours grow in size locally and invade/spread into other brain tissue. Surgery focuses on a tumour's local growth rather than its capacity to invade or spread.

"Probably the most useful thing we [neurosurgeons] do is to debulk and remove a tumour... it makes a real difference to how patients are managed."

Prof Cruickshank pointed out that there are five neurosurgical aims in brain tumour treatment:

- 1. to biopsy
- 2. to reduce symptoms
- 3. to reduce tumour size
- 4. to prolong survival, and
- to introduce treatments/medications directly into the brain.



Neurosurgeon Professor Garth Cruickshank introduces his presentation

Expanding on these individual aims, he explained that tumour biopsies are most commonly performed as part of image-directed 'keyhole' surgery, whereby a surgeon passes instruments through a small (2-3cm) craniotomy hole into the brain. Sometimes this technique can even be performed as a day-case, Prof Cruickshank said. Tumour tissue samples are then analysed genetically and molecularly.

He stressed the importance of surgeons taking multiple biopsies from each tumour. Research is increasingly showing that tumours are heterogeneous and made of several genetically-different cells. Prof Cruickshank then said that the genetic and molecular (biomarker) information gained from biopsy tissue can help diagnose, inform prognosis, and guide future treatment decisions.

The second aim - symptom improvement - is one of "the most useful" outcomes of brain tumour surgery, Prof Cruickshank said, and it can be dramatic even if a tumour is not completely removed. He discussed a 32-year-old male patient with a brain tumour who was experiencing severe headaches and becoming increasingly aggressive toward his family. Even incomplete removal of the tumour led to such an improvement that the patient was "back to normal" after the operation.



Biopsy data later revealed that the tumour was an anaplastic oligodendroglioma with biomarkers that indicated a "relatively good" prognosis and so additional treatments, including further surgery, could be considered.

When thinking about reducing a tumour's size and extending patients' survival (aims 3 and 4), Prof Cruickshank said of low grade gliomas: "I consider them 'pre-malignant' and not stable. Greater than 20% of low grade gliomas are transforming {into a more aggressive tumour} at diagnosis, he said. It is therefore a great challenge to know what the outcome will be.

"You need to think carefully about what you do at diagnosis," he said. The most common problems associated with low grade gliomas include seizures, cognitive problems and fatigue (often due to antiepileptic medication). He explained that even infrequent or mild seizures can have an adverse effect on quality of life by "constantly reminding" the individual that they are living with a brain tumour.

Prof Cruickshank said that the two key questions that need to be considered when attempting to remove a tumour are: "Can the tumour be removed safely?" and "Can we retain quality of life?" Trying to answer aim 4's question (Will this surgery extend life?) is extremely difficult, he said, because there are no randomised controlled clinical trials that have compared the benefit of surgery versus biopsy alone.

Emerging technologies will continue to make surgery safer and more precise, Prof Cruickshank explained. Where a tumour is close to areas of the brain involved in language then surgery can be performed with the patient awake. This allows for direct cortical stimulation (DCS) mapping of these brain regions and study data shows that such intraoperative 'mapping' can halve the rate of neurological deficits.

Other technology, which includes functional MRI (fMRI) mapping techniques, will also allow for better identification of the most important brain regions (such as those involved in movement) and will therefore further help improve the safety of surgery in the future. Prof Cruickshank is currently trialling 'Intraoperative MRI', an approach whereby repeated MRI scans are performed during surgery, allowing surgeons

to precisely assess their progress while they resect a tumour.

Yet despite these advances Prof Cruickshank said that it is still uncertain how much, if any, normal brain tissue should be removed from around a tumour. In principle, removing a margin of healthy tissue from around a tumour should reduce risk of tumour regrowth - but there is no evidence to support or refute this. Prof Cruickshank said that genetic 'profiling' of tumour tissue is starting to reveal that some tumours classified as 'low grade' glioma are highly aggressive.

Again, this new information raises further questions as to how a 'low grade' glioma patient should best be treated - this genetic information is only available after surgery/biopsy.

Cosmetic appearance following surgery is also an important factor that can markedly affect quality of life, but clinicians often neglect to consider it. "You need to think carefully about what you do at diagnosis," Prof Cruickshank repeated.

"Patient advocates can play an important role by asking for all available treatment options at an early stage."

Referring to study data from over 10,000 patients, Prof Cruickshank showed that high grade glioma patients have a better outcome with more aggressive treatment. Patient advocates can play an important role by encouraging patients to ask for all available treatment options





Professor Cruickshank takes neurosurgical questions from the audience

at an early stage, he said. Elderly patients with high grade gliomas should also receive treatment, providing their daily functioning can be preserved.

Prof Cruickshank said that modern image-directed surgical techniques are helping surgeons successfully remove tumours, and intraoperative use of 5-ALA, a fluorescent brain tumour 'marker', improves resection. Paradoxically however, debulking a tumour actually appears to stimulate the remaining tumour tissue to increase its rate of growth, a factor that presumably explains why tumours are more sensitive to radiotherapy after surgery, he said.

"We have to ask patients what their life is about, what is important to them and what their particular concerns are."

Fielding questions from the floor, Prof Cruickshank was asked how a patient's attitude toward risk should be taken into account in risky procedures. "Consent is key," he said, "We [surgeons] have to ask patients what their life is about, what is important to them, and what their particular concerns are – rather than just explaining risks and asking for a signature." The sphere of consent has changed and appreciating the potential gains and risks are particularly relevant in the elderly, he said. "It is important that we, as surgeons, grow up a little bit!"



# Breakaway Discussion Groups: Healthcare Systems and Regional Challenges Including Access to Therapies, Support and Information Delivering the "Brain Tumour Patients' Charter of Rights"

### Setting the Scene

SUMMIT participants were grouped with others from their geographical region to discuss the issues and challenges they and their organisations face with regard to access to therapies, support and information. These forums allowed representatives to compare and contrast their experiences with the hope of being able to develop practical solutions.

Groups also discussed *The Brain Tumour Patients' Charter of Rights* (see pages 70-71), an aspirational document authored by the IBTA in 2010. The Charter was intended as a reference point for patients to use in trying to create an optimal brain tumour journey in the context of their diagnosis.

Individual groups at the Summit then shared summaries from their discussions with the rest of the attendees in a plenary session. The many conclusions from the discussion groups highlighted the diversity of challenges faced in different countries and cultures while emphasising the common purpose of all Summit participants.

### North America

Patient advocacy organisations from North America (USA and Canada) said that challenges facing them included regional disparities in quality of care. Those who do not live near a specialist cancer centre may not receive the best care, for example. Such disparities extend to palliative care, the group said.

Elizabeth Wilson, President and Chief Executive Officer of the American Brain Tumor Association (ABTA), spoke of poll results that indicated that patients feel a great pressure at the time of diagnosis to make decisions about treatments and clinical trial options.

Representatives from Canada furthermore highlighted that there is a lack of clinical trials in their country. Proposed solutions to the challenges facing the USA and Canada included the development of online resources and patient-family financial assistance funds to alleviate financial stress for families affected by a brain tumour diagnosis.

The consensus from the North America discussion group was that the Brain Tumour Patients' Charter of Rights was a good idea but there were questions regarding when the best time would be to present it to patients. The group considered the Charter to be quite long and proposed that some of the points be consolidated. They also highlighted that point 5 ("My option to access care will be based on need, and not

my ability to pay for it.") may raise particular challenges in the USA and Canada given that options for care can be based on medical insurance coverage.



Representatives of North American (US and Canadian) brain tumour patient organisations discuss their heathcare systems' challenges.





Robin Boettcher, left (Pediatric Brain Tumor Foundation, USA) and Rosemary Cashman, right (British Columbia Cancer Association, Canada).



Rosemary Cashman, left, relays to the Summit plenary the main discussion topics in her workshop on healthcare systems and regional challenges.

### Western Europe

The Western Europe group (United Kingdom, Italy, Spain, France, The Netherlands, Belgium, Sweden, Denmark, Ireland, Germany, Cyprus) focused some of their discussion on the disparities of care between children and adults. The group consensus was that children generally receive better care than adults.

Martin Taphoorn, Professor of Neuro-Oncology at the VU University Medical Center, Amsterdam and Leiden University, The Netherlands, shared that there is greater collaboration in pediatric brain tumour care than in adult care in The Netherlands. In France, the watershed between child and adult care is 15 years old, according to Anita Granero of Oscar's Angels.

A particular challenge facing brain tumour patients in mainland Europe is gaining access to 'Centres of Excellence', the group said. The most appropriate brain tumour treatment facilities may be in a neighbouring country and, even after gaining a second opinion, a patient may still be forced to receive care in their own country even though this might not be optimal.

The group raised the question of whether patient advocates should be more proactive in helping their constituents seek the best care with brain tumour specialists regardless of the country in which the best care is located. A long-term solution offered is the creation of a certified and recognised network of 'Centres of Excellence' across Europe ("European Reference Networks", the plans for which are currently



Gordon Oliver, centre left (UK) brings up a point during the discussion session on Western European healthcare systems, regional disparities and The Brain Tumour Patients' Charter of Rights.

in process via the European Commission) that patients would have access to, helping them to decide where to receive the best treatment.

The group said that missed and late brain tumour diagnoses have been an issue in the UK. Brain tumours often have vague and non-specific symptoms. Brain tumour advocacy groups could collaborate to conduct international surveys and research, monitoring speed and quality of diagnosis in different countries, thus encouraging consistency in speed of diagnosis.

It was proposed that the IBTA could operate an information exchange between countries

with the goal of improving brain tumour diagnosis across Europe.



The Western European discussion group on healthcare systems and regional disparities was the largest one at the Summit.



### Eastern Europe

Common themes that emerged from the Eastern Europe group discussion (Croatia, Bulgaria, Turkey, Lithuania) were:

- the need to keep hope alive at all times for those affected by brain tumours, and
- the need for information to be made available in local languages
- variability in quality of care between countries

Issues facing small nations were also described. Some small countries have little or no access to certain treatments. Temozolomide, for example, is not covered by medical insurance in several Eastern European countries. The group also said that there is often no framework for clinical trials and patients are required to travel to other countries to participate in a trial.

The group suggested that brain tumour patient advocacy organisations should collaborate with other rare cancer organisations to pool resources. Intercountry collaboration between brain tumour organisations could also help patients get access to treatments. Petitioning governments to allow access to treatments, such as temozolomide, would also be another positive step that patient advocacy organisations could take.





Above: Justina Smalskiene, left (Lithuania), Dijana Calopek, centre (Croatia) and Valerija Korent, right (Croatia) ponder a point at the Eastern European discussion group on health care systems and inequalities.

Left: Ivan Karagyazov, a university lecturer, is based in Bulgaria and works with the Global Disability Movement.

### Africa, India and The Philippines

A great many disparities were identified in this discussion group (Zimbabwe, The Philippines, Cameroon, South Africa, India). Focusing on The Brain Tumour Patients' Charter of Rights, the group concluded that the aspirational document was more achievable in South Africa and India than in The Philippines, Cameroon or Zimbabwe.

Of the five nations represented, Cameroon and Zimbabwe have effectively no access to treatment, and representatives from those countries (Irene Azong-wara and Christine Mungoshi respectively) raised the question of whether these statements could really be considered 'rights'. There is also no access to clinical trials in these countries, they added. The group said that The Philippines had some access to treatments, but less than in India and South Africa.



Christine Mungoshi of the Zimbabwe Brain Tumour Association (left) and Savita Goswami (right) of the Brain Tumour Foundation of India compare notes in the Africa and Asia discussion group for the regional disparities session at the Summit.



Moreover, statistics on brain tumours are not collected or are incomplete in Zimbabwe, Cameroon and The Philippines, meaning that point 14 of the Charter ("I have the right to ask that my brain tumour is properly registered in my country's cancer registration records, whether it is benign or malignant.") would be unachievable in the short-to-medium term.

Other specific issues facing these regions include widespread beliefs in alternative and traditional folk therapies. Hope for patients should be based on reality rather than false promises, the group said and they discussed the challenge of supporting patients who pursue alternative and traditional folk treatments. Ultimately, the Africa/Asia discussion group concluded that The Brain Tumour Patients' Charter of Rights should be aspired to – but will only be achieved in small steps.



Participants in the Africa and Asia discussion group on regional disparities included, from left to right, Irene Azong-wara (Cameroon), Bonita Suckling (South Africa), Susan Abbott (The Philippines) and Will Abbott (The Philippines)



### Australasia and Eastern Asia

The Australasia/Eastern Asia discussion group also focused on The Brain Tumour Patients' Charter of Rights, identifying how they felt it could be further improved. Like other groups, the Australasia/Eastern Asia discussion group felt that the document should be shortened, but on the proviso that it wasn't "watered down".

They suggested that a separate document should be prepared for children with brain tumours which would take into account the different issues facing younger people.

The group also discussed whether the document would benefit from a different title: the notion of 'rights' could be seen as too legalistic, potentially suggesting that there would be negative consequences if not met.

Melissa Lim from Singapore also explained that the current political situation in her country meant that 'Charter of Rights' had negative connotations. They proposed that a new 'master document' could be written that could be extracted from and



Chris Tse (New Zealand, far left) and Melissa Lim (Singapore, second from the left), led the discussion group comprised of representatives from Australasia and Eastern Asia.

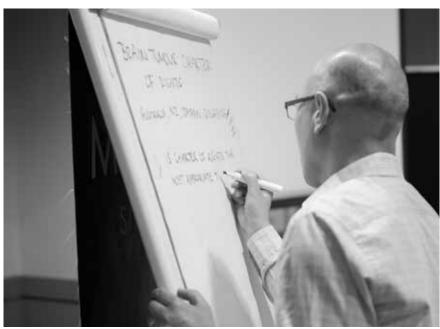


modified to draw up 'Charters' appropriate for each culture and country.

The Brain Tumour Patients' Charter of Rights appears to be most relevant at initial diagnosis, the group said. A document for ongoing and end-of-life care should be considered. The group also felt that the "right to be treated according to my risk profile" ought to be included in any future Charter, thus taking into account patients with a poor prognosis who are prepared to try riskier treatments.



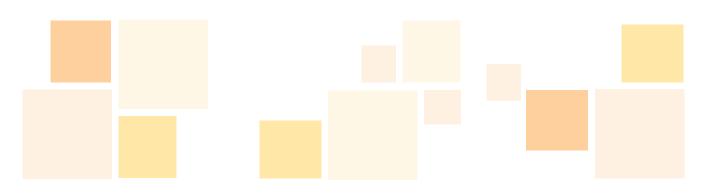
IBTA Advisor Sally Payne (Australia), seated to the right of Chris Tse (standing), attended the discussion group on regional disparities. Also in this group were: Yuko Moue (Japan), Barrie Littlefield (Australia), Susan Pitt (Australia) and Melissa Lim (Singapore).



The Australasia and Eastern Asia group discussed The Brain Tumour Patients' Charter of Rights and how that might be relevant to their part of the world.

### The Brain Tumour Patients' Charter of Rights

There are a number of documents dealing with patients' rights, some of which touch on the rights listed in the IBTA's Charter. But the IBTA Charter has been drafted from the point of view of the brain tumour patient with particular consideration for the difficulties which sometimes arise in the brain tumour journey. The IBTA has sought to ensure that the Charter will have worldwide relevance but we are mindful that many countries lack basic health facilities and the specialists and facilities relevant to the treatment of brain tumours. The Charter therefore represents an aspirational ideal which we should work towards. While asserting our rights we acknowledge that no rights can exist in human society without responsibilities.





### Keynote presentation -Dr Sonja Marjanovic (United Kingdom)

### The Use of Quality of Life Measures in the Treatment and Care of Brain Tumour Patients: Current Practice, Challenges and Opportunities

### **Key points:**

- Measuring quality of life is deliberately subjective and usually focuses on the patient's experiences.
- Quality of life is rarely assessed in routine brain tumour care although interest in measuring it is growing.
- We know very little about how quality of life issues affect the treatment and care of patients with brain tumours, because of a lack of evidence
- Many quality of life assessments tools exist, and we need to better understand which types of tools would be most effective in different care contexts, for example for different stages of cancer and different health systems.
- Use of quality of life tools in brain tumour patients holds much promise and patient advocates can be drivers of change.

Dr SONJA Marjanovic is a Research Leader at the not-for-profit policy research organisation RAND Europe, whose mission is to help improve policy and decision-making through research and analysis.

She introduced an on-going exploratory project that is examining the use of quality of life assessment measures in the treatment and care of patients with cancer, with a particular focus on brain tumour patients. It is hoped that the results from the project will be used to create an evidence base that will inform future care and policy for brain tumour patients.

She explained that quality of life (QoL) refers to a person's general wellbeing and is multifaceted, including physical, social, and psychological elements. QoL assessment tools generally take the form of questionnaires looking at a patient's



Dr Sonja Marjanovic from RAND Europe presented at the Summit on "The use of quality of life measures in the treatment and care of brain tumour patients: current practice, challenges and opportunities"

perspective on one or more aspects of their quality of life, she said. They are deliberately subjective, and may have particular importance for patients whose survival prospects are limited. Dr Marjanovic highlighted that in such cases, patients may be willing to accept different trade-offs between the potential adverse effects of treatments and their quality of life. Dr Marjanovic explained that the current research project aims to find out whether or not QoL measurement tools are being used in patient care and, if so, when, how and why. Importantly, the study aims to find out whether there is evidence that using QoL assessments results in any meaningful differences for patient treatment, care and well-being.

At the time of this Summit, the researchers were reviewing the published literature on the use and impact of QoL assessment tools in the care and treatment of cancer patients. They were also conducting interviews with experts from a range of countries. The study focused on Western Europe and Canada but is intended to also identify issues which future studies could expand on and investigate across a broader range of country contexts, Dr Marjanovic explained.

Discussing initial, emerging insights from the ongoing literature review search, Marjanovic said that "the landscape seems to be patchy and fragmented". RAND Europe's initial data gathering and analysis







identified a relatively small number of studies on the use of QoL tools in care settings, and the studies seemed to be of variable quality and produced inconclusive findings. She stressed that there is a need for more high quality research, that will identify when and with whom improvements to QoL can be made through interventions. She suggested that better evidence would be needed for making clinical decisions and empowering patients to engage with QoL tools and information from them.

"We need more high
quality studies into Quality
of Life and how tools for
measuring it can impact
on cancer patients
and their care"

Dr Marjanovic said that the QoL tools that currently exist and which could be used in cancer care vary in complexity, and that a scoping analysis suggests their use seems to be inconsistent across countries. She noted that QoL assessments seem to be rarely performed in routine brain tumour care, despite their increasing use in clinical trials. RAND's study is looking into the evidence behind these initial assumptions.

The RAND Europe research project is interested in better understanding the potential of these tools to provide more robust evidence and inform treatment decisions. The project is looking at the different types of factors which can influence whether the tools are used or not in care settings, and how they could impact on patient-physician communication and on treatment and care decisions. For example, the project is exploring how issues such as awareness of the tools, training needs for their effective use, time-demands on health professionals and patients, the availability of guidelines, and the role of patients in healthcare decision-making, influence the use and impact of QoL tools.

Encouragingly, interest in measuring quality of life is growing and QoL assessments in neuro-oncology have great potential to inform care, Dr Marjanovic said, but there are challenges to overcome before this is done routinely in clinical care. RAND Europe was exploring the key issues which would be important for policy, healthcare professionals, industry and patient advocacy to address. Dr Marjanovic noted that patient advocates could have an important role in the future of these tools and in providing a patient perspective on the most effective ways to use them, but more evidence is needed on how this could be facilitated

All Summit participants were invited to complete an anonymous consultation survey of their experiences and opinions of quality of life assessments and these results will be fed into the final report findings, which is due to be published in 2016.

There followed a lively exchange of comments and questions from Summit participants.

The RAND Europe study is expected to be completed soon and the findings are expected to be made available in early to mid-2016.









Savita Goswami (Brain Tumour Foundation of India). Savita asked whether scoring quality of life in an assessment has real value, given that results from a one-to-one consultation may yield very different answers to a written questionnaire.

Above far left: IBTA Chair Kathy Oliver listens to the quality of life presentation by Dr Sonja Marjanovic

Above centre left: Dr Sarah Parks, from RAND Europe

Left: Dr Marjanovic said that the QoL assessments in neuro-oncology have great potential to guide research and overall care, but a lot more work needs to be done.



Dr Marjanovic acknowledged the ongoing debate over the value of QoL tools and the need for a degree of customisation to different contexts - including cultural. However she also pointed out that the factor that is being measured may be more universal (e.g. such as emotional states, ability to carry out daily activities) but the way of arriving at the measure and the types of questions asked to arrive at a measure may be more context-specific. She acknowledged that some degree of standardisation in tools would though be important to facilitate conclusions about effects from specific treatments on different types of patients and cancer profiles.

In response to further questions, Dr Marjanovic suggested that there may be a need for QoL assessments to consider caregivers and for questionnaires that specifically consider 'quality of death' in the end-stages of life. This is not the explicit focus of the RAND Europe project, but an associated issue of potential importance for policy.



Above: Gordon Oliver, Co-Director of the IBTA

Gordon Oliver (UK) queried whether the act of completing a questionnaire may negatively impact quality of life; Dr Marjanovic acknowledged this point, and said that the timing of a questionnaire, for example, could be important and needs to be considered as part of the assessment process.

Mary Lovely (USA) shared her experiences of working with QoL tools throughout her over-20-year career as a neuro-oncology clinical and research nurse, stating that many physicians with



Above: Dr Mary Lovely (an IBTA Senior Advisor and specialist neuro-oncology nurse from the USA), makes a point. To Mary's right is Mary Ellen Maher (also an IBTA Senior Advisor and specialist neuro-oncology nurse from the USA). To Mary's left is Dr Claus Thielert, Director, Clinical Science & Medical Affairs, MagForce AG (Germany)

whom she has worked have seen little value in QoL assessments. But she spoke positively of using QoL tools, such as the distress scale, saying that she has observed meaningful and consistent results when it is applied to large numbers of patients.

Quality of life (QoL) refers to a person's general wellbeing and is multifaceted

Current QoL tools used in cancer care vary in complexity

QoL assessments have great potential to inform care

Interest in measuring quality of life is growing



### Discussion groups on Quality of Life for Brain Tumour Patients

### Setting the Scene

Following Dr Marjanovic's presentation, five discussion groups of randomly assigned Summit participants were each given one hour to talk about quality of life issues that affect brain tumour patients and caregivers, with the opportunity to propose answers to challenges faced. Groups were asked to consider how health related quality of life can be defined, measured and improved. Specific attention was also given to cultural differences and how these differences may impact such issues.

Conclusions and key points from each group's discussion on quality of life were reported back to the entire Summit in a plenary review. Some of the important findings are summarised below.

Q1: When thinking about the brain tumour population, what is a comprehensive, working definition of health related quality of life (HRQoL)? Would the same definition apply to patients and caregivers or are there differences? Are there important cultural differences that would influence the definition?

All groups felt that there were key cultural differences between countries (and even within a single country) that can have a powerful effect on quality of life. For example, some cultures have a strong tradition of respect for the family unit; and some enshrine the tradition of eldercare. In these cultures, care of the patient may be more accepted and natural, and





Mary Lovely, PhD, RN, CNRN, and Mary Ellen Maher, RN, APN, CNRN, facilitating one of the group discussions on quality of life.

entail less sense of restriction on the part of the patient and the family members.

However, some cultures such as those in Cameroon see illness, especially cancer, as shameful and a "loss of face." In this instance, support from sources outside the family unit is not sought even when it is needed. However in Zimbabwe it was noted that the desire for "protection" from the diagnosis, and difficult conversations, may also include keeping information from the patient and families.

"Some cultures...
see illness, especially
cancer, as shameful and
a 'loss of face."

All discussion groups reported back that an understanding of terms and definitions will

Left: Members of one quality of life discussion group.
Left to right: Stu Farrimond (IBTA's Digital Technology
Advisor - UK), Sarah Parks (RAND Europe), Professor
Martin Taphoom (The Netherlands), Francesca Berrini
(Associazione Italiana Tumori Cerebrali ONLUS, AITC, Italy),
Ivan Karagyazov (Global Disability Movement, Bulgaria)

be perceived differently among countries and cultures, presenting challenges when trying to standardise health related quality of life measures internationally. The words 'quality of life' and 'well-being' are inherently imprecise and would need clear definitions so as to standardise any measuring tool.

One group suggested that 'happiness' could be used as an indicator for measuring and defining quality of life, while another group



The Summit delegate from Cameroon, Irene Azong-wara.



Christine Mungoshi from the Zimbabwe Brain Tumour Association (ZBTA).





Julia Schwarzenberger from Deutsche Hirntumorhilfe (Germany) and Kate Ferguson from Northern Ireland (Brainwaves NI) lead one of the quality of life discussion groups.

said that an assessment of quality of life should be based on an individual's personal values, rather than using strict categorisations.

Moreover, representatives from India and Japan explained that in their cultures face-to-face communication gives markedly more meaningful and consistent assessment of quality of life than written scales. "You listen with your ears, eyes and heart," Yuko Moue (Japan) said.



One of the quality of life discussion groups at the Summit considers how culture might influence quality of life.

Q2: How do you approach a situation where a patient's view of quality of life differs from that of their loved ones (e.g. the patient is trying to live/work at prediagnosis level while the family may be encouraging a slower, more tempered pace, or vice-versa).

Teenagers and young adults, however, will have more complex priorities and may be prevented from experiencing critical social interactions and meeting important developmental milestones (graduation, learning to drive, etc) because of a brain tumour. And due to their youth, they may lack adaptive psychosocial skills and support networks, making them more vulnerable to depression and suicide, one group said. This in turn may exacerbate the distress of their family members.

Groups also identified that a caregiver's needs and perspectives will also be different to that of a patient. Some participants said that the caregivers often require more support than the patient. One group shared the findings of an online survey showing that brain tumour patients



At the Summit all participants were involved in quality of life discussions and brought their various perspectives, cultural and otherwise, to the table. Pictured here are, left to right, Dr Kate Worthington (Celldex Senior Medical Director), Melissa Lim (a brain tumour patient and founder of Brain Tumour Society Singapore), Susan Pitt (Secretary, Brain Tumour Alliance Australia).

It was identified that a caregiver's needs and perspectives will also be different to that of a patient.

had better coping mechanisms than their loved ones.

There were a variety of suggestions for resolving conflicts between patients and their loved ones when their views of quality of life differ. Breaking down the issues and encouraging good and open communication was seen as key, with some Summit participants speaking of the need for patients and their families to acknowledge their fears and transition to a 'new normal'. Additional external help may also be needed. One group said that in the end-of-life phase, the patient's QoL needs to be prioritised over that of their family.



Q3: How can the definition and characteristics of HRQoL direct future research into brain tumours and the development of better and more effective treatments?

It was a unanimous finding from all of the discussion groups that HRQoL can, and should, be used to develop better and more effective treatments. Quality of life measures are being used increasingly in clinical

research, several groups said, although it is usually seen as an 'additional extra' rather than a primary outcome.

Some participants argued that HRQoL should be used as a primary endpoint in treatment research. "We do not give life, we give days to the life," one participant said.

One group said that certain medical drugs have been withdrawn because they have increased length of life but worsened quality of life, demonstrating the importance of HROoL measures.

Side effects of treatments need to be considered in any HRQoL measure. One group described how social media and biographical interviews can offer insights into how daily life is affected over time in ways that paper-based questionnaires cannot.

Q4: Beyond the practical tasks of providing medical care, facilitating appropriate referrals to care services and other relevant medical specialties, can health care professionals truly have an impact on improving a patient and/or family's HRQoL?

Reports from individual discussion groups revealed a breadth of suggestions as to how health professionals and patient advocates can improve the HRQoL of patients and their families. Some participants felt that many doctors seem uninterested in discussing their patients' psychological and social wellbeing. Conversely, more than one clinician at the Summit expressed their frustration that most patients whom they see in clinic are not interested in discussing their quality of life – they only want to know the test results.

Allowing for additional clinic sessions to discuss wider quality of life issues was offered as one potential solution to this problem, notwithstanding the logistical and staffing challenges. One participant said that doctors' abilities to communicate is vital but varies greatly, thus reinforcing the importance of involving different people with different skills in patient care.

### "Listening is key"

It was widely reported from the group discussions that listening is key: many patients may have a strong desire to stay at home for end of life care for example, which could be crucial in improving patient and



Maureen Daniels (IBTA Senior Advisor and Coordinator of the Gerry and Nancy Pencer Brain Tumor Centre in Toronto, Canada) said: "There is also some responsibility on the part of patients to maximise quality of life."

family QoL. Some patients may also want to leave a legacy and, hence, facilitating this will positively impact QoL.

"Rehabilitation" was expressed as an important concept – empowering patients and their families to manage their circumstances as well as possible. Giving patients control over their treatment options was also seen as important for maximising a patient's QoL. In open discussion, Maureen Daniels (Canada) said: "There is also some responsibility on the part of patients to maximise quality of life." One participant also argued that by increasing a patient's value of life, their quality of life will improve – and this is something with which advocates can help.

On-going support was seen as very important, which could include financial support, travel assistance and help with day-to-day tasks. Patient organisations can assist with many of these aspects. Bonita Suckling (South Africa) said: "The bottom-line is that quality of life is linked



Bonita Suckling (founder of Rainbows and Smiles in South Africa) commented: "The bottom-line is that quality of life is linked to resources – having money."

to resources – having money. This is very sad and we need to work as an alliance to pressure for resources and money to be put where it is needed."

To read the full IBTA Summit Report, please visit

https://issuu.com/ ibta-org/docs/ibta\_ summit\_report\_2015



CBTRUS provides a resource for timely, updated statistical data for all Primary Brain and Central Nervous System Tumors from population—based cancer registries in the United States.

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

- Board of Medical Advisers: Dr. Gerardo D. Legaspi, NeuroSurgeon (SLMC, TMC, UP-PGH)
- Dr. Gerardo H. Cornelio, Oncologist(SLMC, SJDD, UP-PGH)
- Dr. Santosh Kesari, NeuroOncologist/Neurologist, Moores Cancer Center (MCC), UCSD
- Mr. Marlon Saria, AOCNS Onco Nurse Specialist, MCC LICSD
- MCC, UCSD

  Dr. Luis Martin Habana,
  Cardiologist (TMC, CGN,
  UP-PGH)
- William C. Abbott / Susan T. Abbott, Founding Director/ Co-Director

EMAIL ADDRESS: wcabbott@gmail.com, hca7sta@yahoo.com

**IF WE ARE ON FACEBOOK:** Philippine Brain Tumor Alliance and 'LIKE' us!



### 50 Shades of Grey Matter

Melissa Lim, President, Brain Tumour Society (Singapore)



BRAIN Tumour Society (Singapore) also known as BTSS commemorated our second year with a second Brain Tumour Awareness Campaign themed "50 Shades of Grey Matter" or "50 SGM".

Apart from catching attention with its cheeky title, the campaign conveyed a more serious message that 'Brain tumours do not discriminate' so patients come from all walks of life, which is so aptly symbolised by '50 Shades of Grey Matter'. The number 50 was symbolic that the campaign was held in 2015, the 50th year of Singapore's independence.

The 50 SGM Campaign was held over three months, beginning 31 August 2015 with awareness campaigns in four public Singapore hospitals. The objective of the hospital awareness campaigns is to raise

BTSS' profile with healthcare professionals and inform them of our mission to connect, befriend and empower brain tumour patients. A BTSS booth was set up at each hospital on the designated awareness day to share our beneficiaries' stories of 'Living Strong' while visitors to our booth were encouraged to leave their finger prints on our 50 SGM montage as a pledge of their support to BTSS and our awareness campaign.

The finale of our Brain Tumour Awareness campaign was our signature "Brainy Car Rally" and "Brainy Joy Ride" for paediatric brain tumour patients on Singapore's second Brain Tumour Awareness Day.

On 8th Nov 2015, 30 Lamborghini Supercars gathered at Suntec Singapore



Convention & Exhibition Centre in spectacular formations that attracted a lot of interest from the public while volunteers and beneficiaries mingled happily as they waited in great anticipation for the flag-off.

The program started on a high note with a rousing musical performance by Musical Theatre Limited, followed by speeches by the BTSS President and our Guests of Honour. After the thrilling countdown to flag-off, our beneficiaries sped off for their joy rides through Singapore's famous Orchard Road to spread the word for Brain Tumour Awareness.



### Western Australia Walk and Picnic

THE Brain Tumour Association of Western Australia held their inaugural walk and picnic on 25 October 2015. Coinciding with International Brain Tumour Awareness Week, money was raised from donations and selling Christmas cards. Funds were put towards Professor

Anna Nowak's research at the University of Western Australia. Everyone enjoyed the day which will become an annual event. 106 kms were walked and then "donated" to the IBTA's Walk Around the World for Brain Tumours.

See www.braintumourwa.com

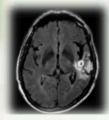




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**Northwest Bio** proudly supports the IBTA's advocacy for brain tumor patients around the world in their battle to beat brain cancer.

Together, we can shine a spotlight on the need for new treatment options and for more clinical trials of experimental brain cancer treatments, which may provide patients and their families renewed hope and encouragement.



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### A Kids' Brain Tumor Cure Foundation: driving forward research for the most common forms of pediatric brain tumors

Amy J. Weinstein, Executive Director A Kids' Brain Tumor Cure, United States



BRAIN tumors are the number one cause of cancer-related death in children and current treatments are toxic, cause permanent cognitive and physical impairments, and severely diminish the quality of life for children who are battling brain tumors.

When four families founded A Kids' Brain Tumor Cure Foundation (AKBTC), also known as the Pediatric Low Grade Astrocytoma (PLGA) Foundation, in 2007, their goals included bringing awareness to this disease while raising research dollars for an area that has been woefully underfunded and under-researched.

According to Dr. Charles Stiles, PhD, Professor of Neurobiology at Harvard Medical School and co-director of the Dana-Farber/ Harvard Cancer Center's program on Brain Cancer Research: "Pediatric low grade astrocytomas have, by and large, escaped the attention of the biomedical research community. The lack of government and pharmaceutical industry sponsored research has led to a lack of mouse models and clinical tissue samples. In order to understand pediatric astrocytomas, we have to change this. The support and long-term commitment of AKBTC Foundation is crucial to the development of new, lifesaving therapies."

#### Searching for a cure

Over the last nine years, AKBTC has been a driving force in the search for pediatric brain cancer causes and treatments, raising over US \$15.5 million, which has been leveraged to



drive forward a targeted research agenda and accelerate the pace of scientific research.

With AKBTC support, the first-ever dedicated PLGA research program was established at the Dana-Farber Cancer Institute. Targeted scientific studies at 23 other medical institutions around the globe have been funded. Project grants vary in duration and award amount, and funding for over three dozen basic and translational research grants and four clinical trials has helped drive interest in this disease sector and attract many of the most talented scientific/ clinical minds in the world. Moreover, AKBTC has galvanized the international research community to focus on this rare disease by sponsoring six international pediatric neuro-oncology conferences, resulting in four international research collaborations.

While providing 'seed funding' for researchers to test the most promising novel concepts is the impetus for AKBTC funding, the ultimate goal is for the researchers to not only prove efficacy of their research, but to

follow up with a successful grant application to the National Cancer Institute (NCI). Within the last five years, four research projects have resulted in NCI approved funding, thereby resulting in an additional US \$15 - \$20 million in funds available.

#### **Pushing the boundaries**

"Due to AKBTC's seed funding, we have made critical progress on promising research which will drive our application for significant funding from the NCI," said Miguel Rivera, MD, Assistant Professor of Pathology at Massachusetts General Hospital, Center for Cancer Research in the United States.

With the guidance of a Scientific Advisory Board comprised of medical/scientific experts from a wide range of 'best in class' medical institutions and disciplines within the oncology field, AKBTC continues to push the boundaries of traditional science/clinical thinking to find common genetic alterations in PLGA and other brain tumors, which will enable the design of more personalized and effective treatments for



Above: Young PLGA brain tumor survivors/supporters at the Geared Up For Kids fundraising event

children battling all forms of brain tumours.

"Changing the landscape for this disease has not been easy, and certainly would not have been possible without the incredible support of individuals and families from across the globe that have recognized the need for a focused research agenda in order to bring hope to those children that are battling today...and tomorrow," said AKBTC Board President, Al Janower.

He added: "Only through our united fundraising efforts have we been able to support the researchers who are determined to make a difference."

#### Collaboration across the globe

Whether a family creates a personal fundraising page, holds a community event or joins one of AKBTC's existing fundraising events,

the collective impact has been astonishing. Working together, uniting new families and new friends under one fundraising and awareness-raising umbrella will continue to ensure that AKBTC can support the most promising research projects in the future.

AKBTC actively promotes partnerships with other non-profit organizations, families, individuals, government entities, as well as public and private medical institutions across the globe, in order to leverage collaborations, ensure the most productive use of funding resources and minimize duplicative research efforts, which might otherwise waste precious resources and further delay finding new treatments. Kick-starting these partnerships will accelerate the advances in research and treatment options available to all children battling brain tumors.

We can't fight this battle alone.

For further information, please visit the AKBTC website at www. akidsbraintumorcure.org or email them at contact@akidsbraintumorcure.org



Providing Support and Raising Awareness of Brain Tumours in Ireland

www.braintumourireland.com Email: info@braintumourireland.com



**GFME 14 years** 

GFME, Glioblastoma Fundation Michele Esnault, established in 2001 is a French-based (Marseille), patient-oriented, support group involved in brain tumors. GFME translates and publishes in French scientific publications of Pubmed and ASCO on primary brain tumors. The association gives support, help, guidance on treatments and clinical trials for adults and children diagnosed with brain tumor. GFME works in partnership with ARTC, Brain Tumor Association For Research to rise funds. GFME is a website <a href="http://gfme.free.fr">http://gfme.free.fr</a> a quarterly magazine, a phone assistance (33) 04.91.64.55.86, and two mailing-lists (gfme@yahoogroupes.fr \_ and astrocytome-gfme@yahoogroupes.fr). The group includes 650 patients, care givers, friends and family members around the globe. For more details gfme@free.fr

### Peace of Mind: How an Arts-Based Support Group Helped Brain Tumour Patients Reframe

Catherine Dunlop, Ph.D., DVATI,
British Columbia Cancer Agency, British Columbia, Canada

I AM an art therapist and I would like to tell you about an arts-based support group we held at the British Columbia Cancer Agency (BCCA) for patients who have been diagnosed with a primary brain tumour.

The group came about through a request from the BCCA Patient & Family Advisory Council (PFAC), which is comprised of brain tumour patients and their loved ones. PFAC provides guidance, feedback, and advocacy in order to improve overall care for the brain tumour population.

In the spirit of improving care, the members of PFAC suggested we begin offering art therapy to brain turnour patients. The rationale: art therapy provides another important resource for this population to express themselves, cope with their illness, and seek support.

The Arts-Based Support Group for Brain Tumour Patients started in the fall of 2014. The objectives of the group included:

- to support relief of emotional distress around coping with cancer;
- to provide a venue for expression through art; and
- to create a space for participants to form connections and offer support to one another.

I co-facilitated the group with Amy Rappaport, a social worker at BCCA with extensive experience of working with the brain tumour community. Each group took place over six sessions, scheduled one week apart. Art projects included:

- drawing portraits (without looking);
- sketching landscapes with a white oil pastel and revealing them with watercolour;
- mixed media layered paintings (collages) on wooden boards;
- and nylon and wire sculptures.

The group also worked on a collaborative art project in pairs: transforming radiation masks into sculptures they titled, "The



**Above**: Art therapist Catherine Dunlop helped to run an arts-based support group for brain tumour patients in Canada

Warrior", "the Braindeer Trickster", "More or Less Me" and "Brain Cancer Got Me Thinking."

We also worked on additional activities such as journaling (visual and writing), and imaginal dialogue (connecting with an image through internal and written dialogue and getting guidance from a place of inner knowing).

A feedback survey was administered on the final day of the group. Participants were also contacted six weeks after the group ended with an invitation to provide follow-up feedback about the arts-based support group and any outcomes they might have experienced.

Here is a sample of how the participants described their experience in the group:

- "I felt more relaxed and less anxious after every art therapy class."
- "The way Cathie and Amy supported and communicated and silenced everyone's inner critic is a helpful tool for everyday life."
- "I loved being around people somewhat going through the same scary cancer that I am."

"Doing art with fellow patients. It's like a calming meditation with a level of comfort and informal discussion with other patients and long-term survivors."

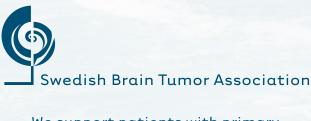
Six weeks later, participants mentioned these outcomes:

- "The collage that I created in class is beside my bed and it calms and centers me anytime I need it."
- "I have taken the art skills learned in class and applied them to my own projects at home."
- Through the collage/painting. I have a permanent piece that symbolizes some of my thoughts about cancer. I also learned some things about myself through this process that were unexpected and might not have arisen in any other way."

The feedback shows how an arts-based support group for patients with a primary brain tumour can be a positive experience for participants, helping them to reframe through shifts from judgment to joy, and from disconnecting to connecting.



Above: Working with an image using "imaginal dialogue", an approach which asks the questions: Who are you? (I am the one who...), Where have you come from? What is your gift for me? What is your guidance for me going forward?



We support patients with primary brain tumors and every one who can relate to this group.

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Meetings and events

Advocating

Support of research (not yet launched)



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- share valuable experience between healthcare workers and patients
- increase public awareness of this patient group.

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### PBTN

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We are the network of groups of the pediatric brain tumour patients and their families in Japan, who help each other to improve our quality of life through peer support and discussion on our web site, through organising a summer camp and by appealing to the government etc.

For more information, see the website addresses below.

### **Child Brain Tumor Parents Support Group**

http://www.pbtn.jp

#### "Child Brain Stem Glioma Network

http://glioma-net.com/page6

#### "cranio park"

(for craniopharyngioma patients and families) http://cranio-park.fc2-rentalserver.com/

### Pediatric Brain Tumour Support Group in Kinki prefecture

http://miracle-brain.jimdo.com/

#### **Japan Brain Tumour Alliance (JBTA)**

http://www.jbta.net/

## Measuring health-related quality of life in brain tumour patients: benefits and problems

### Linda Dirven, PhD

Leiden University Medical Center, Leiden, The Netherlands

#### What is health-related quality of life?

Although treatment with surgery, radiotherapy and/or chemotherapy does not yet result in cure, prolonged survival can be achieved in glioma patients. The incurable nature of this disease has resulted in health-related quality of life (HRQoL) becoming an important outcome measure in glioma research. Indeed, for glioma patients, palliation and the maintenance or improvement of HRQoL are considered at least as important as prolonged survival.

HRQoL refers to the impact of an individual's health on the different dimensions of life, and may be altered by a medical condition or medical treatment. These different dimensions are reflected in HRQoL outcome measures, by including domains covering physical, cognitive, role, emotional and social functioning, as well as symptoms induced by the disease and its treatments.

HRQoL is a patient-reported outcome measure, meaning that it reflects the patient's perspective, and is typically measured with self-report questionnaires. The most frequently used questionnaires in cancer research are the:

- European Organisation for Research and Treatment of Cancer (EORTC) QLQ-C30
- Functional Assessment of Cancer Therapy (FACT) and the
- MD Anderson Symptom Inventory (MDASI)

These questionnaires cover general problems and symptoms that are related to cancer and its treatment (for example fatigue, nausea and vomiting, depression and bodily pain).

However, because brain tumour patients not only have cancer, but also a neurological disease, they have



Above: Dr Linda Dirven is a senior researcher in neurology with a special interest in health-related quality of life for brain tumour patients.

symptoms and problems that are different from other cancer patients; these include seizures, motor dysfunction, problems with memory and concentration, or changes in personality and behaviour. It is therefore necessary to supplement these generic HRQoL questionnaires with a brain tumour-specific module.

### Value of HRQoL assessments in clinical trials and clinical practice

HRQoL assessments are important in both brain tumour clinical trials and in daily clinical practice.

In clinical trials, HRQoL assessments can be used to determine the so-called 'net clinical benefit'. This means that the benefits of a new treatment strategy (e.g., longer survival duration) have to be carefully weighed against the negative effects of that treatment on the HRQoL

Based on this information, the physician can decide whether the new treatment strategy is better than the standard treatment.

Ideally, a new treatment strategy will result in prolonged survival without a negative impact on HRQoL. However, it is possible that a new treatment strategy results in a longer survival duration, but worse HRQoL. Or the other way around: a new treatment strategy results in a shorter survival duration, but improvement of HROoL.

In these situations, it is difficult to decide what to opt for. And who should make the decision? A possible solution is if the physician and the patients make the decision together (i.e., 'shared decision-making') using the best available evidence, while taking into account the patient's clinical and other characteristics (such as age, tumour type and location, and health status) as well as the patient's preferences.

In daily clinical practice, HRQoL assessments can be used to monitor the patient's functioning during the disease pathway. Regular assessment of HRQoL provides the physician with information on the impact of a specific treatment strategy in an individual patient. Intended and unintended adverse effects of the treatment can be monitored, and if these problems require follow-up, symptom treatment can be initiated or patients can be referred to another relevant health care professional. In addition, regular HRQoL assessments can increase the physician's awareness of the patient's functioning and well-being. This may subsequently improve the communication between the patient and the physician during follow-up consultations.

### Problems in measuring and interpreting HROoL

Although information on HRQoL is very valuable in brain tumour research, there may be some problems with the assessment of HRQoL that makes the interpretation of the results difficult.

A first challenge is caused by cognitive problems (problems in memory or concentration) that many brain tumour patients experience during the course of their disease. Patient ratings of their own HRQoL may therefore not always be an accurate reflection of their true functioning and symptom experience. Often patients feel that their HRQoL is good, while their family members disagree. A potential solution for this problem may therefore be to use 'proxy ratings', meaning that a family member or relative provides the information on the patients' HRQoL.

Another problem with HRQoL assessment is missing data. Missing data can occur in two ways: missing a complete HRQoL questionnaire or missing one question within a questionnaire. Complete questionnaires can be missing when a patient misses a follow-up appointment with the physician. This is often due to the poor health status of the patient, progression of the disease, death of the patient, or when a patient no longer wishes to complete HRQoL questionnaires. One question within

a questionnaire can be missing when a patient unintentionally misses a question or chooses not to answer a particular question for personal reasons.

A consequence of missing data is that HRQoL results about the effect of a specific treatment strategy may be inaccurate, leading to wrong conclusions.

#### **Summary**

Despite some difficulties in measuring and interpreting results, HRQoL continues to be an important outcome measure in brain tumour trials and clinical practice. Results of HRQoL assessments, whether measured in clinical trials or in clinical practice, do not only provide the physician with relevant information, but also the patient and his/her relatives.

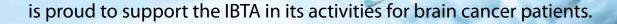
HRQoL scores may improve the communication between the physician and patients and subsequently facilitate shared decision-making, which may ultimately result in better treatment choices for the patient. It is therefore important for all parties involved that patients continue to complete HRQoL questionnaires.

# Northeast Florida Brain Tumor Support Group (United States)



MEMBERS of The Sontag
Foundation's Brain Tumor Support
Group of Northeast Florida took part
in Walk Around the World for Brain
Tumours throughout May 2015,
wearing pedometers and recording
the distance covered. The group
donated an impressive 2,569 miles to
the World Walk tally.





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### V Simposio Día Internacional de la Concientización en Tumores Cerebrales activities in Bucaramanga, Colombia 2015

International Brain Tumour Awareness Day 2015 Symposium

Gabriel Vargas, MD, Neurosurgeon, Symposium Organiser Colombia, South America





**Above**: The V Simposio Día Internacional De La Conscientización En Tumores Cerebrales attracted 300 participants.

FOR the fifth year in a row, supporting the International Brain Tumour Awareness Week 2015, we met on 7th November 2015 in the city of Bucaramanga, Colombia.

The event "V SIMPOSIO DÍA INTERNACIONAL DE LA CONCIENTIZACION EN TUMORES CEREBRALES" was held at the Mayor Auditorium of the University of Santander (Universidad de Santander) UDES, with the support of Clínica Chicamocha of Bucaramanga, Oncological Neurosurgery Section of the Latin American Federation of Neurosurgical Societies (Capítulo de Neurocirugía Oncológica de la Federación Latinoamericana de Sociedades de Neurocirugía FLANC), Neurooncology and Base of Skull Section of the Colombian

Association of Neurosurgery (Capítulo de Neurocirugía Oncológica y Base de Cráneo de la Asociación Colombiana de Neurocirugía) and SNOLA (Society for Neuro Oncology Latin America).

On October 4th, 2015 the UDES Neurosurgery research group, family, friends and oncological patients who promoted the 5th International Brain Tumour Awareness Day Symposium, participated in the "11th City of Bucaramanga Marathon 2015 FCV".

On November 7th, from 8 am to 4 pm, physicians and health professionals interested in the topic, medical students, oncological patients and their relatives attended different interdisciplinary academic lectures given by a group of experts in each

one of the topics regarding: "Advances in the Diagnosis and Treatment of Brain Tumors".

After an opening ceremony by the Medical Education Coordinator of the UDES School of Medicine, and the elected President of the Colombian Association of Neurosurgery, we proceeded with various interdisciplinary academic lectures given by a select international and national group of speakers.

We conducted web conference lectures from Brazil and Argentina. The UDES neurosurgery research group students gave a speech explaining the purpose and objectives of the International Brain Tumour Alliance (IBTA) and shared updates about UDES' research advances regarding risk factors for brain tumors. Other lectures included clinical features, surgical strategies,

radiotherapy, oncologic stereotactic radiosurgery and palliative care for intrinsic brain tumors and pituitary adenomas.

Finally a patient specialising in psychology gave a tremendous and exciting point of view, on behalf of other oncological patients, on the difficulties and hopes regarding brain tumours.

The audience numbered 300 registered people, the event was free of cost and it was supported by commercial partners.

Next year we invite you all to our 6th International Brain Tumour Awareness Day Symposium in Bucaramanga, Colombia on October 28th and 29th, 2016 in support of the International Brain Tumour Awareness Week 2016.

All event details from the Bucaramanga Awareness Day Symposium can be viewed on these webpages: www.neurocirugiaoncologic aflanc.blogspot.com www.neurooncologiaybasede craneoacncx.blogspot.com



**Above**: Go Team UDES! Students of the neurosurgical research group of the Universidad de Santander (UDES), friends, family and oncological patients, at the 11th City of Bucaramanga Marathon 2015, promoting International Brain Tumour Awareness week.

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.





### Elisa's fight

### Adéline Cendres

Toulouse, France

EVERYTHING began in the spring of 2012.

Our daughter, Elisa, was 21 months old. She started to systematically vomit her morning bottle. As she was going to nursery school doctors told us it was a rhinopharyngitis or gastroenteritis.

But very rapidly her walking skills regressed. She often fell and complained of "head boo-boo" as she called it.

Elisa was less and less interactive with her little friends at the nursery school. On 13th June 2012, when she turned 22 months, we were so worried that we went to the emergency room at the hospital.

After some tests, including a scan, the doctors gave us the terrible news: Elisa had a "big mass" in her brain.

We were in shock and the doctors' grave faces confirmed the gravity of the situation.

We lived in Albi, a town about one hour from Toulouse, in the south of France. Very rapidly the SMUR (Service Mobile d'Urgence et Reanimation - literally translated as Mobile Emergency and Resuscitation Service) - which are mobile intensive care units - came and took my daughter and me to the Children's Hospital of Toulouse. In the meantime, in a big rush, my husband went to get our eldest daughter from school, and some personal belongings from home.

#### We finally receive the diagnosis

Everything happened very fast. The surgeon came to see us telling us that he had to place a ventriculo-peritoneal shunt to help drain away the fluid and rapidly relieve our daughter. The anaesthesiologist came to us too. Elisa had neuro-surgery the following day.

Elisa was better but the "big" surgery to remove the brain tumor happened five days later. Anita, a hospital volunteer from the local charity Oscar's Angels, came to talk to us about the surgery and tried to reassure us during this very long and stressful period of waiting.

Elisa spent a few days in the intensive



Above: Elisa, in 2012, before diagnosis

care unit at the hospital where she had many convulsions. It was very difficult for us because she was not well and we couldn't stay with her during the nights.

Then the result came and it was devastating: AT/RT, atypical teratoid rhabdoid tumor, a highly malignant brain tumor.

What the doctors were saying was very hard to accept. They talked about a very aggressive turnor with a very poor prognosis. The therapy protocol was very long and included chemotherapy, radiotherapy and more chemotherapy. They said they would do everything they could to save Elisa. We were scared of losing her and it was unbearable for us.

#### Treatment for AT/RT begins

So we started chemotherapy in the oncology department. The first MRI confirmed that Elisa's tumor was sensitive to the chemotherapy and we started to hope. Finally good news! We had to be strong, it was going to be a long journey but we had to keep going for our daughter.

At the beginning Elisa couldn't swallow the pills so they put in a naso-gastric tube that she kept for few months for the medicines and food as she didn't want to eat anymore. That was



Above: Elisa during her treatment in 2014

replaced with a gastrostomy tube which was a great relief for all of us. Treatment went on for months, chemotherapy after chemotherapy, aplasia after aplasia. I lived in the hospital with Elisa. After two months my husband had to go back to work and our eldest daughter had to go back to school.

Radiotherapy went well even if Elisa had to be sedated for the 30 sessions, and she became very familiar with the gas used for this, calling it "canard" ("duck")!

At the beginning of the year (2013) Elisa had a serious complication. After high dose chemotherapy and a transplant of her own stem cells she developed a hepatic portal vein obstruction and we almost lost her twice. She had to spend more time in the intensive care unit and my husband had to stop working again.

In March 2013 an MRI showed some white spots and we feared a relapse. Fortunately, after four further months of anguish another MRI confirmed that it was radionecrosis and not tumor growth.

#### Living the "new normal"

During this time we had to stay positive for Elisa. She was giving us a lesson in life: always ready to play and sing even when she was at her lowest.

During this very trying time Oscar's Angels volunteers were always available and were a great support.

Our own parents allowed us to take some time and be with our eldest daughter who was four years old and needed us too. She was our ray of sunshine. On the other hand we changed our circle of friends, developing new ones. We were constantly with Elisa. We reassured her, sang songs and held her hand to make her fall asleep.

After nine months in the hospital we finally went back home to finish the chemotherapy treatment. Doctors told us to send Elisa back to school part-time to allow her to socialize again. She had to have extensive physiotherapy because as her tumor was on the cerebellum, after the surgery she couldn't walk anymore and her learning was greatly impaired.

#### Life as it is now

As of today Elisa has balance problems. She is slow in her movements and comprehension and has swallowing difficulties. But even if she still has serious cognitive problems Elisa can



Above: 2015 - a little girl who never gives up!

walk and, thanks to growth hormone therapy, she is growing again!

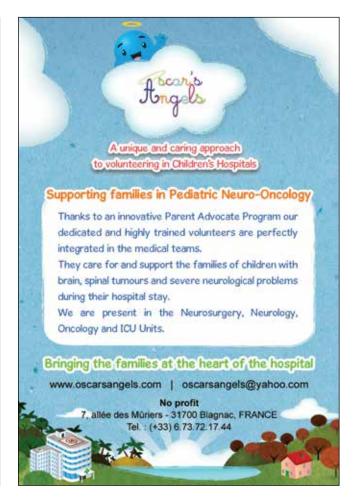
Elisa goes to school part-time five days a week with a special needs assistant and has a full rehabilitation program: physiotherapy, psychomotor therapy, orthoptist and speech therapy.

We are aware that we are very lucky

to still have our little "champion" with us. Elisa is free-spirited; she has never given up and was always strong. She has been in remission for almost two years now and we hope that it will continue that way.

Life goes on and the four of us are very happy and grateful to be together!





### Julián's journey

### Erika Mendoza El Salvador, Central America

WE are a family of five: Mom, Dad, Agustín who is 15, Nicolás who is 12, and our little one, Julián, now 11.

At the age of three, Julián was diagnosed with a "cerebral lesion", specifically a thalamic lesion. It was discovered by accident, or may I say, by fortune, while X-raying his cranium after a fall. Never in our minds would we have imagined that someone in our family would have to endure a process of this nature, especially not our healthy, energetic, filled-with-life three year old.

So, Julián had a brain tumor, and this is where our story begins. The first two years were basically asymptomatic. Julián walked, swam, spoke. It was almost as if the tumor wasn't there - until it hemorrhaged occasionally, which reminded us it was there, as it caused symptoms and revealed itself as active.

After two years of observation and MRI follow-up, Julián underwent two procedures. One was a craniotomy to remove the tumor which had grown, and the other was to place a valve, as the tumor had caused severe inflammation and hydrocephaly. This was the first time the tumor was biopsied, and the pathologic reports revealed a DNET, disembrioplastic neuroepithelial tumor, a grade I glioma.

Six months later, Julián underwent chemotherapy, due to tumor dissemination to meningeal tissue and his spinal cord. He received vincristine and carboplatin for a year, which was surprisingly well tolerated, with few symptoms and a good outcome, as the tumor activity was greatly weakened.

After almost three more years of observation and follow-up, Julián suffered a massive brain hemorrhage which left him with permanent neurological consequences. He endured three very hard months at the hospital, during



**Above**: Julián and his mother, Erika Mendoza de Rivera

and after which we were all in awe of the tremendous courage, strength and perseverance that he showed.

Julián had to re-learn how to swallow, communicate, move, take steps, walk. But he bounced right back. A few months after that, however, he presented with severe back pain, and a new MRI revealed an aggressively growing lesion in the spinal cord, which severely compromised his life.

A new chemotherapy treatment



**Above**: Julián never complains and has taught his family how to see life in a different light

followed, along with palliative care, which included large doses of morphine, but nothing seemed to work. The spinal lesion left Julián confined to a wheelchair at this time, and he has never regained the ability to walk since. It was at this time that we decided to take yet another palliative treatment that was offered to us. Fourteen radiotherapy sessions, holding on

Below: Goal! Julián is once again full of life



to our faith in God and in our heaven-sent angels, Dr. Eduardo Lovo and Dr. Victor Caceros.

To have a better quality of life - that was the treatment goal, best case scenario, and what we had accepted after this long and painful journey. Never would we have thought that Julián would have yet another miraculous recovery. It was as if radiation was a high strength dose. He was completely off morphine and any painkillers two months after the treatment, and it's been a year and a half since that. His year of temozolomide treatment finished on December 12th, 2015.

So, all we can say is thank you... thank you God. Julián is back to school, on a regular schedule. He's even on the student council and full of life! He continues his physical therapy, has never complained, and is a true gift of life and hope that God has given us. How lucky we are!

When one is faced with a diagnosis of this sort, there's a lot of fear, but you learn to live with it, accept it, and see life in a different light. God shows Himself in different and amazing ways - through people, doctors, treatments. For me and my family, it really has been a blessing in disguise.

It has also shown us to appreciate the great value that we have in El Salvador, the wonderful physicians, their professionalism, how much they care, how much they give themselves to their patients.

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





Tumor Network

YUKO Moue, Vice President of the Pediatric Brain Tumor Network in Japan, was joined by 42 paediatric brain tumour patients and caregivers for the April 2015 Gold Ribbon Walk in Tokyo. Walking through Tokyo's Hibiya Park and Palace Park to raise awareness for childhood cancer, the Network's group collectively walked 210 km which they donated to the IBTA's Walk Around the World for Brain Tumours.





ZIMBABWE BRAIN TUMOUR ASSOCIATION 76 McChlery Ave, Easlea ,Harare Zimbabwe +263 774 168 535

Brain Tumours still remain a taboo subject not only in Zimbabwe but in the Southern African region. There appears to be a lack of clear understanding of Brain Tumours and how the disease manifests which brings conflicting beliefs among

traditional levels of our society.

The Zimbabwe Brain Tumour Association in 2016 has set a goal to revive and inspire hope through awareness campaigns and support group meetings to educate all people on the causes, signs, symptoms and effects of Brain Tumours.

With improved knowledge, there will be better understanding of Brain Tumours for every level of our society will to early detection, better prognosis and treatment the disease.

### Achieving Through Hope &

Email: zbta@mweb.co.zw



### Rebecca's story

### Jennifer Gouchie-Terris New Brunswick, Canada

THE past year has been life-changing for Rebecca Schofield and her family.

Diagnosed with a medulloblastoma on February 9, 2015, less than 24 hours later the 16-year-old Riverview, New Brunswick teen underwent a seven-and-a-half hour surgery to remove the large mass at the base of her skull followed by 30 radiation treatments and eight cycles of chemotherapy at the IWK Heath Centre in Halifax, Nova Scotia, Canada.

Treatment recently ended but Rebecca remembers all too well that fateful evening last year when an emergency CT scan revealed she had a brain tumour. What started out as flu-like symptoms eventually turned into so much pain that she insisted her parents take her to the hospital. She hadn't been feeling well for a while but never expected the devastating diagnosis.

It was a tough 12-month journey for the teen who struggled with nausea and fatigue so severe that it often resulted in hospitalization. Ongoing mobility and balance issues have made it difficult for Rebecca to walk, and side effects of chemotherapy led to almost weekly blood and platelet transfusions.

Shortly after being diagnosed, Rebecca decided to give her tumour a name. A silly, frivolous name that didn't induce fear in herself or others: "Butterscotch".

"I thought it needed a name," said Rebecca. "But one that wasn't too scary since having a tumour can be scary enough."

Rebecca and her family have done a great job raising awareness of brain tumours by sharing their story with the local media at every opportunity. She even created a Facebook page called Becca's Battle with Butterscotch as a way of sharing her brain cancer journey and enabling people to follow her story as she dealt with the many obstacles that came her way while remaining positive.



Above: Rebecca Schofield and her mom, Anne

The Schofields say that they are forever grateful and humbled by the unwavering support of their family, friends and community and countless acts of kindness bestowed upon them, often by total strangers.

A number of fundraising events have been hosted in benefit of the family and last fall, more than 200 students at Rebecca's high school came together to produce a touching video featuring her classmates holding up signs of support to Rachel Platten's song, *Stand By You*. Created by her best friend Danielle, the video has helped Rebecca get through some very difficult times.

"I just watch it when I'm feeling down and it makes me feel better just to know that all of those people care." Rebecca said.

Although there were days when she felt like giving up, Rebecca has amazed even herself with the strength she's been able to muster when the going got tough.

She said: "Never give up because even if you don't think you can do it, there's more in you than you know. I never would have thought I'd be able to do this and look at me now."

Rebecca added: "Every day we try to

find something positive. Some days are harder than others but we focus on what we can control and what we can't control, we let go."

Her cancer experience has inspired her to become a motivational speaker and perhaps even write a book some day called *Butterscotch Pie and Other Bittersweet Things*.

One thing Rebecca has been able to control is her positive attitude.

"It's called cancer, not can't-cer," she said. "Don't accept the limitations that people give you because of your diagnosis. That is for you to decide."

Rebecca had a clear MRI back in February and now that treatment has officially ended, she is anxious to get on with life. She's looking forward to going back to school, spending time with her friends and being a "normal" teen again.

The following inspirational quote sums up how Rebecca feels.

"The greatest battle is not physical but psychological.

The demons telling us to give up when we push ourselves to the limit can never be silenced for good. They must always be answered by the quiet, the steady dignity that simply refuses to give in. Courage.

We all suffer. Keep going."

Graeme Fife



### 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 Salpëtrière Fédération de Neurologie – Mazarin 47, Boulevard de l'Hôpital 75013 PARIS

### www.artc.asso.fr





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

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

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



# New WHO Classification of Brain Tumours: major theme at the 8th Annual Meeting of the Indian Society of Neuro Oncology (ISNO) Meeting

Dr Chilukuri Srinivas, Organising Secretary of ISNOCON 2016 and Dr Rakesh Jalali, President, ISNO India

THE Indian Society of Neuro-oncology (ISNO) held its 8th annual meeting in Hyderabad from 1st -3rd April 2016.

More than 400 delegates from various parts of India and eleven international speakers attended the meeting. India, being the land of diversity, has a few hospitals with world-class facilities at par with leading institutions around the globe. But at the same time there are many centres with only basic facilities. One of the major challenges our Indian society has faced thus far has been to bridge this gap and to create ways of communication and cooperation among various oncologists and institutes.

The theme of this year's event was the updated WHO classification of brain tumours, which incorporates specific molecular markers and will be adopted worldwide. The existing classification is based primarily on histopathology, which in turn is based on understanding how different a tumour cell is from a normal cell.

The newer classification will lead to a better understanding of brain tumours based on biological changes rather than just the morphology. When specific alterations such as the IDH mutation or a TERT mutation happens in normal cells, they live, grow and divide without the usual controls normal cells have. The impact of the newer WHO classification is likely to be significant and will be incorporated in all clinical trial designs.

Speakers in this dedicated session jointly conducted by ISNO and the Neuropathology Society of India highlighted the molecular pathology developments during the recent decade and summarised their major impact which



Above: Dr Rakesh Jalali (right) presents the Ab Guha Oration Plaque to Dr Patrick Wen (left) at the ISNO meeting.

has been incorporated in the updated WHO classification. A talk on minimum pathology reporting in the Indian context by Dr. Chitra Sarkar and Dr. Vani Santosh drew a fair amount of attention among the attendees. This half-day session ended with a panel discussion addressing specific concerns by the clinician and pathology community in India.

ISNO will produce a document with clear guidelines about pathology reporting in accordance with the new WHO classification and incorporating minimum and desired testing. This document will be disseminated throughout the country and discussed at various fora in the next year or so.

The yearly "Do Not Miss" session included four high impact research highlights from the recent past: the novel Tumour Treating Fields (TTF) trial in glioblastoma, TCGA (The Cancer Genome Atlas) and RTOG 9802 trial data in low grade gliomas as well as the recent

molecular insights into ependymomas.

Other sessions included discussions on optimal management of benign brain tumours, the direction of current neuro-oncology research including immunology, immunotherapeutics, radiogenomics and brain metastasis. The session for negotiating palliative care in neuro-oncology in the context of cultural and linguistic diversity focussed on the gaps and social stigma in this field as well as the need for a greater commitment to the concept of palliative care in neuro-oncology.

Interactive parts of the programme included "Hard Talk" sessions that involved probing the expert for a deeper understanding of newer philosophies, the role of the tumour board and debates on chemotherapy, VEGF inhibition and surgical mapping versus image guidance.

Dr. Patrick Wen (Director of Neuro Oncology at Dana-Farber Cancer Insitute in the US) delivered the prestigious, annual Ab Guha Oration and spoke on recent advances in therapies for gliomas - challenges and opportunities.

The presidential oration was delivered by Dr. Sandip Chatterjee and dealt with the sensitive issue of the doctor-patient relationship, its evolution and where the relationship is headed. Both the orations were highly memorable and appreciated by everyone.

Thirty of the top scoring abstracts were chosen for podium presentations and covered wide areas of basic and clinical neuro-oncology research.

JASCAP (Jeet Association for Aid in Cancer Patients), an NGO dedicated to spreading awareness about cancer among patients and the public, in association with the Brain Tumour Foundation of India (BTF India), unveiled a patient education book on brain tumours in Telugu (the local language in Hyderabad and the third most spoken Indian language). ISNO members pledged their commitment to publish these books in most other native Indian languages in the next few years.

### Starry Night 8.5K Events





STARRY Night 8.5K walks/runs benefit the Pediatric Brain Tumor Foundation in the United States and in 2015 took place in seven cities: San Francisco, Los Angeles, Houston, Chicago, Atlanta, Philadelphia and Boston. The PBTF says that there are more than 28,000 children in the US who are living with a brain tumor and the Starry Night events raise awareness of this as well as raising funds for family support programs and for cutting-edge medical research into childhood brain tumours. Further information can be found here: www.curethekids.org



We help patients and family! Join us!
We want to improve the quality of life of patients!

www.asate.es info@asate.es



## A mother, a daughter and the challenge of brain tumours in Nigeria

### Shade Adoh Buckinghamshire, United Kingdom

Shade Adoh is a registered nurse living and working in the UK. Her mother, Marian Adeleye, manages a clinic near Lagos, Nigeria, where brain tumour patients go for help. Shade - who is also a district counselor, school governor and Chair of Nigerian Women in Buckinghamshire – is dedicated to helping minority groups obtain better access to healthcare. She hopes that one day a specific patient organization will exist for brain tumours in Nigeria.

BRAIN tumours - or any tumours for that matter - continue to be a challenge for the average Nigerian who is also struggling with overcoming everyday life hurdles such as financial challenges, security, peace of mind, general health and just about anything and everything that human beings all over the world have to grapple with day in, day out.

My own interest in the area of brain tumours is based on a couple of months I spent in the neurosciences ward at the John Radcliffe Hospital in Oxford (UK) as a locum nurse. Comparing the care that brain tumour patients received there with how patients fared in a country like Nigeria was, of course, like comparing night with day.

### One woman's crusade to bring healthcare to people in Nigeria

My amazing mother, Marian Adeleye, operates a small clinic located in a remote area outside Lagos, Nigeria. She is not a doctor but simply a member of the community who originally decided to set up a clinic so women could give birth safely and so that minor medical cases could be treated effectively. There is an on-call doctor at the clinic who is employed by my mother.



Above: Shade Adoh

But due to the difficult situation in the surrounding community and the lack of medical facilities, everyone attends my mother's clinic irrespective of their ailment, including people with brain tumours. My mother is a compassionate woman and often does not charge patients for their care, but wants to see them treated rather than sending them away because they don't have the means to pay for medical help. The doctor constantly complains about my mother asking him to see patients who cannot pay and obviously this poses its own dilemmas about the sustainability of my mother's much-indemand and vital clinic.

### Significant challenges

The cost of medical care in Nigeria is a huge problem. People have to decide either to pay for an MRI or feed their family even knowing full well that there is a tumour in their brain or somewhere else in their body.

I have been privileged to speak to



**Above**: Marian Adeleye runs a clinic in Nigeria to which brain tumour and many other patients turn for help

Professor Isa Hussaini of the University of Maiduguri, Nigeria who is also a visiting Professor at the University of Virginia. I also spoke with Dr Okezie Kanu, a consultant neurosurgeon at Lagos University Teaching Hospital who was introduced to me by a very good friend and brother, Dr Ajayi, formerly of Llandough Hospital in Wales (UK) but now based in Lagos. Professor Hussaini and Dr Kanu both alluded to the issue of diagnosis from the perspective of non-availability of diagnostic tools dependent on the part of Nigeria in which one lives.

There is also the issue of no MRI scans because most Nigerian people are too poor to pay for scans even if machines are available. Delayed diagnosis is mainly based on the affordability of scans rather than lack of awareness, which is a secondary factor. Misdiagnosis is another area of concern which also delays correct diagnosis. In addition, tumour samples



Above: The Marian Adeleye Medical Centre near Lagos, Nigeria

and specimens must be sent abroad for pathological review.

There are experts in the field of neurosurgery in Nigeria but arguably not enough to deal with a vast and increasing population. Some neurosurgeons have to travel great distances to see brain tumour cases, from the south to the east for example, and the cost of this must be paid by the patient.

In addition, most medical professionals in Nigeria have to self-fund their own continuing medical education and knowledge updates in order to meet their patients' needs. Training of all professionals involved in identifying, treating and monitoring brain tumour patients should be better facilitated.

### The crucial importance of a brain tumour patient group

Most important of all, and about which Dr Kanu and I strongly agree, is the need for brain tumour patient support, advocacy and information groups. Currently, there are no such groups. There are, however, some private foundations established by people with personal experiences of illness and which provide financial support to patients recommended by the consultants.

Dr Kanu and I both believe that setting up a group which is truly representative of brain tumour patients will create awareness, provide support to patients and families, provide the opportunity to share experiences and fund-raise to purchase desperately-needed equipment and resources.

Such groups, in time, will raise the profile of brain tumours in Nigeria and perhaps, in partnership with other patient organisations, will engage with the ministry of health and the wider community to tackle cancer-related issues in the country.

Based on anecdotal evidence and in speaking with my mother and the two medical professionals I've mentioned, data about the incidence and prevalence of brain tumours in Nigeria would also appear to be seriously lacking. If there was a brain tumour patient group or groups they could volunteer their time in helping collect such data, archiving records or collating information so that a detailed assessment of the situation for brain tumour patients in Nigeria can be made and planned interventions commenced.

To date, my mother's clinic has seen over 20 people with brain tumours who couldn't be helped due to their late presentation. When patients are referred to the bigger centres they are unable to pay for their scans so they return to my mother for financial support which she sometimes funds but not for long, as there are travel costs to be incurred and the family's daily living expenses too. All of these financial pressures usually result in the patient not seeking further treatment and in some cases using the money they are given to feed their family instead of seeking further medical treatment for themselves.

It is a terrible situation.

### Where there is a will, there is a way...

My conclusion is this. A brain tumour patient group must be set up in Nigeria with specialist nurses able to care for this group of desperately deserving people. Effective and affordable pain management is also paramount as is the need to share information between neurosurgeons and other practitioners who care for people with brain tumours in order to devise a protocol/referral process for this challenging pathway.

I recently met with Kathy Oliver (Chair and Co-Director) and Jenny Baker (a Senior Advisor) from the International Brain Tumour Alliance (IBTA) and Christine Mungoshi who established the Zimbabwe Brain Tumour Association after her little girl was diagnosed with a brain tumour in Harare. We discussed what could be done for brain tumour patients in sub-Saharan Africa. I pray that one day, a specific support group for these patients might emerge in Nigeria which will help them deal with the significant problems they face, not only on a medical basis but on a financial and societal basis as well.

I am very grateful to Professor Hussaini and Dr Kanu for sharing their thoughts with me on this subject.

In the meantime, I grow more every day to appreciate my mother's amazing dedication to her patients in Nigeria. Like her, I believe that where there is a will there is a way.

The IBTA has contacts in 113 countries throughout the world to whom it makes available its free monthly electronic news and its free annual magazine, Brain Tumour

### Meagan's Walk: then, now, next

### Blair Day, Meagan's Walk Volunteer Toronto, Canada

IN 2016, Meagan's Walk celebrates its 15th year of creating a Circle of Hope. A retrospective of the organization truly demonstrates all that can be accomplished when a community, united in hope, comes together.

### About Meagan and Meagan's Walk

Meagan Bebenek was four years old when she was diagnosed with brain stem glioma. In June 2001, two weeks after her fifth birthday, Meagan died at The Hospital for Sick Children ("SickKids") in Toronto, Canada. As Meagan's mother, Denise, left the hospital that day, she envisaged a real yet symbolic "hug" of the hospital as sending a message that those children and families touched by serious illness are never alone. Meagan's legacy is Meagan's Walk: Creating a Circle of Hope.

Meagan's Walk is an event for all ages and abilities and takes place annually on Mother's Day weekend every May. The 5 km walk from the Lake Ontario waterfront to SickKids, wends through downtown Toronto, past the CN Tower, Rogers Centre, the Air Canada Centre, the edge of the financial district and then along broad University Avenue, to the hospital. There, thousands of participants join hands to "hug" the building, creating a "circle of hope".

In 2002, at the first Walk, an estimated 800 participants braved driving rain, thunderstorms and extreme winds. Fingertip to fingertip, the determined group of walkers formed that first "hug". Meagan's Walk 2015 saw 4000 supporters enjoy a sunny, warm spring day. The first walk raised \$80,000 and the most recent total was over \$400,000. Now over \$4 million has been raised to further brain tumour research, leading to new therapeutic approaches, less toxic treatments and improved outcomes for young patients.

### Community and research involvement

Throughout the year activities in the community promote awareness about



Above: Children always enjoy taking part in Meagan's Walk.

Meagan's Walk as various groups organize events and fundraising activities to support this mission of hope. Meagan's Walks participates in school events, leading to a newer awareness in students that everyone, regardless of age, can make a difference. With a focus on leadership skills, students learn that every school community has someone in their midst who struggles and needs their compassionate support. Kids helping kids!

The Arthur and Sonia Labatt Brain Tumour Research Centre (BTRC) at SickKids is the world's largest paediatric brain tumour centre, with scientists dedicated to the determination of the molecular causes underlying brain tumours and the discovery of new therapeutic

approaches that can be rapidly translated to patients. The "bench to bedside" philosophy is reflected in the "Meagan Marie Bebenek Walking Bridge", a tribute to the significant contribution made over the years by the Meagan's Walk community of supporters. This bridge spans Elizabeth Street, and links SickKids to the research centre.

Funds raised through Meagan's Walk result in breakthroughs at SickKids. "There is no question that without the support of Meagan's Walk over the last decade we would not be considered one of the top paediatric brain tumour research centres in the world," said Dr. Christian Smith, Ph.D., Operations Manager, BTRC.

Below: Young participants in Meagan's Walk hold signs that tell a little bit about their stories - whether they have lived with a brain tumour themselves, or lost someone who they loved, like a brother or sister with a brain tumour.



Established in 1998 with only four labs and 27 researchers, today the BTRC comprises 11 labs, and over 100 researchers. Funds raised through Meagan's Walk have supported research into new, less toxic treatments for children, helping them to live healthier lives.

Meagan's Walk moves into the future focused on further collaborative work of the world's top brain tumour experts and anticipates the research leading to newer therapeutic approaches for young patients around the globe.

### Helping researchers move closer to a cure

Recent developments propelling Meagan's Walk include the Meagan's Walk National Collaborative Grant Competition. "Seed" money will enable researchers to get promising studies underway and to collaborate with the world's top paediatric brain tumour scientists.

In 2014-15, Dr. Alvaro Lassaletta, a paediatric haematologist from Madrid came to SickKids for the Meagan Bebenek Neuro-oncology Fellowship. His year-long research led in part to his being awarded a fellowship in Cape Town, South Africa to continue



Above: "Myah's Wings" - just one of the very large groups of families and friends participating in Meagan's Walk.

research on low grade glioma. However, Dr. Lassaletta has remained in Toronto where he continues several research projects.

Dr Michael Zapotocky is the Meagan Bebenek Fellow for 2015-2016. A graduate of Charles University, Prague, Dr. Zapotocky completed his Ph.D studies in the field of molecular biology of acute myeloid leukemia. In Toronto Dr Zapotocky is involved in a research project of non-invasive detection of tumour specific mutations in patients' blood, with the goal of evaluating patterns in metastatic disease and correlating this to medulloblastoma molecular subgroups.

### We've only just begun

The Meagan's Walk community of supporters will continue to remind young patients and their families that they are not alone in their struggle, and continue to raise awareness of paediatric brain tumours and the need for expanded research and improved treatments. Finally, we shall also continue to raise funds for research at the BTRC which will lead to improved treatments and outcomes for young patients.

We have come so far, yet there is so much more we can do. Our efforts have only just begun.



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### Brain tumour patient and caregiver advocacy, support, fundraising and information organisations and initiatives

### AUSTRALIA

ACT Brain Tumour Network Email btaa@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.btaa.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/canceremotional-support/brain-tumour-support/

Cure Brain Cancer Foundation http://www.curebraincancer.org.au

Grey Matters

www.greymatters.org.au

Neuro-Oncology Information Network - NOglN http://www.sydneybrainandspinesurgeons.com.au/nogin.html

**Newro Foundation** 

http://www.newrofoundation.com.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-othercancers-1735452683351613/

#### **CANADA**

BC Cancer Agency http://www.bccancer.bc.ca

3-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

Gerry and Nancy Pencer Brain Tumor Centre http://www.pencerbraintrust.com/

Joe di Palma Brain Tumor Foundation www.joedipalmafoundation.com

Meagan's Walk: Creating a Circle of Hope www.meaganswalk.com

Tali's Fund

www.taldoron.com

### CAYMAN ISLANDS

Brain Tumour Foundation (Cayman Islands) "The Forgotten"

http://www.btfcaymanislands.com

### CROATIA

Croatian Brain Tumor Association - GLIA www.glia.hr

#### CYPRUS

Cyprus Brain Tumour Association (CBTA) https://www.facebook.com/cbta.cyprus

#### DENMARK

HjernetumorForeningen

http://www.cancer.dk/hjernetumorforeningen/

### EL SALVADOR

Gris Positivo

http://grispositivo.org

### 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 Fundation Michèle Esnault http://gfme.free.fr/

Imagine for Margo

http://imagineformargo.org/en

Oscar's Angels

www.oscarsangels.com

### GERMANY

Deutsche Hirntumorhilfe eV www.hirntumorhilfe.de

#### INDIA

Brain Tumour Foundation of India www.braintumourindia.org

### IRELAND

**Brain Tumour Ireland** 

http://www.braintumourireland.com/bti/

The Irish Brain Tumour Support Group www.irishbraintumoursupport.org

### ITALY

Associazione Italiana Tumori Cerebrali ONLUS http://www.tumoricerebrali.it/

BrainLife

www.brainlife.org

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-Glioblastomamultiforme-cancro-al-cervello-57560022151/

#### JAPAN

Japan Pediatric Brain Tumor Network www2.pbtn.jp

### LEBANON

CHANCE -

Children AgaiNst CancEr http://www.beirut.com/I/25407

### LITHUANIA

Kartu Lengviau

www.kartulengviau.lt/joomla/pradzia.html

### NETHERLANDS

Hersentletsel.nl

http://www.hersenletsel.nl

Hersentumor.nl/ http://hersentumor.nl/

STOPhersentumoren.nl

NORWAY

Hjernesvulstforeningen www.hjernesvulst.no

PHILIPPINES

Philippines Brain Tumour Alliance

http://www.facebook.com/pages/Philippine-Brain-Tumor-Alliance/139492062749160/

SINGAPORE

Brain Tumour Society (Singapore) http://braintumoursociety.org.sg

SOUTH AFRICA

Rainbows and Smiles

http://www.rainbowsandsmiles.org.za

Brain Tumour Foundation South Africa http://braincatalogue.blogspot.co.uk/

SPAIN

Association 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 hjärntumörföreningen) www.hjarntumorforeningen.se

SWITZERLAND

Kinderkrebs Schweiz

http://www.kinderkrebshilfe.ch

TAIWAN

Childhood Brain Tumour Association of Taiwan (CBTA) http://www.cbta.org.tw

TURKEY

Turkiye Beyin Tumoru Hasta ve Yakinlari Demegi (Brain Tumour Patient & Caregivers' Association of Turkey) https://www.facebook.com/tbthyd/

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

**BT Buddies** 

www.btbuddies.org.uk

Charlie's Challenge www.charlieschallenge.com

Clowns in the Sky

http://www.clownsinthesky.org/

East Kent Brain Tumour Support Group https://www.facebook.com/EKBTSG/

**Ed Evans Foundation** 

www.edevansfoundation.co.uk

Ellie's Fund - Brain Tumour Trust

Fighting Ependymoma

http://www.fightingependymoma.org.uk

Headcase

www.headcase.org.uk

Katie McKerracher Trust

www.katiemckerrachertrust.co.uk

Levi's Star

http://www.freewebs.com/levisstar/

Meningioma UK www.meningiomauk.org

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.thornemasontrust.co.uk/

Tuberous Sclerosis Association www.tuberous-sclerosis.org

Worcestershire Brain Tumour Support Group http://www.braintumoursupport.co.uk/ worcestershire.html

UNITED STATES

Accelerate Brain Cancer Cure

www.abc2.org

Addi's Faith Foundation www.addisfaithfoundation.org

Adult Ependymoma

https://sites.google.com/site/adultependymoma/

A Kid's Brain Tumor Cure

(AKBTC)

http://akidsbraintumorcure.org

American Brain Tumor Association (ABTA)

www.abta.org

Angels Among Us http://dccc.convio.net/site/

PageServer?pagename=angels\_home

Ben and Catherine Ivy Foundation

www.ivyfoundation.org

Benny's World

http://www.bennysworld.org/

**Brad Kaminsky Foundation** 

www.tbkf.org

Brain Candy Project www.braincandyproject.org

Brain Science Foundation www.brainsciencefoundation.org

Brain Tumor Foundation www.braintumorfoundation.org

Brain Tumor Foundation for Children

Brain Tumor Fund for the Carolinas

www.braintumorkids.org

http://www.btfcnc.org/about/overview.cfm

Brain Tumor Support Group of Northeast Florida http://resources.caregiver.com/listing/brain-tumorsupport-group-of-northeast-florida.html

Brains Together for a Cure

www.brainstogetherforacure.org
Brian Bedell 2 Young Foundation

http://www.2yf.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 -

CNJBTSG

www.njbt.org/startCNJBTSG.cfm

**Charles Warren** 

Brain Tumor Awareness Foundation www.charleswarrenfoundation.org

Childhood Brain Tumor Foundation www.childhoodbraintumor.org

Children's Brain Tumor Foundation

www.cbtf.org

Chordoma Foundation

http://www.chordomafoundation.org

Chris Elliott Fund/ EndBrainCancer Initiative www.chriselliottfund.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.drmarnierose.org/ https://www.facebook.com/ drmarnierosefoundation/

**Emory Brain Tumor Support Group** 

www.neurosurgery.emory.edu/BTSG/contact.htm

Ependyparents online support group http://braintrust.org/groups/ependyparents/

Epidermoid Brain Tumor Society (Online) http://epidermoidbraintumorsociety.org/

Florida Brain Tumor Association

http://www.floridabraintumor.com/homepage.htm

Gray Matters Foundation www.graymattersfoundation.com

Head for the Cure Foundation www.headforthecure.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/

Lauren's Foundation

http://laurensfoundation.org/fitzys-5k-run/

**Legacy Brain Foundation** 

http://www.legacybrainfoundation.com/

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 G Belz Foundation

http://mgbf.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/

Oklahoma Brain Tumor Foundation

www.okbtf.org

Pediatric Brain Tumor Foundation http://www.curethekids.org/

ROC On! Run Over Cancer http://www.roconnow.com/

San Diego Brain Tumor Foundation

www.sdbtf.org

Sontag Foundation and Brain Tumor Network (BTN)

https://sontagfoundation.org http://www.braintumornetwork.org

Southeastern Brain Tumor Foundation

http://sbtf.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

Walk for Kate and Blankets for Brains http://www.walkforkate.org/about.html

We Can Pediatric Brain Tumor Network www.wecan.cc/We\_Can/Home.html

Western North Carolina Brain Tumour Support www.wncbraintumor.org

### ZIMBABWE

Zimbabwe Brain Tumor Association (ZBTA) https://www.facebook.com/Zimbabwe-Brain-Tumor-Association-225796887464934/





and the

INTERNATIONAL
BRAIN TUMOUR
AWARENESS WEEK

1st January - 31st December 2016

22nd - 29th October 2016

These two projects are being repeated for the tenth year in a row in 2016. The IBTA requires no financial commitment from your organisation to be a supporter.

Contact <a href="mailto:chair@theibta.org">chair@theibta.org</a>

YOUR SUPPORT OF THESE TWO POPULAR GLOBAL EVENTS WILL FURTHER HELP BRAIN TUMOUR PATIENTS TO DEAL WITH THE CHALLENGES THEY FACE.

# BRAN TUMOURS



www.theibta.org

International Brain Tumour Awareness Week: 22nd - 29th OCTOBER 2016.