



# Brain Tumour

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

Proud mother  
Stefania Distanto  
celebrates a  
very special  
Mother's Day  
and shares her  
inspirational story

■ **INTERNATIONAL  
LOW GRADE  
GLIOMA  
REGISTRY**

■ **ALL.CAN INITIATIVE -  
STRIVING FOR  
GREATER  
EFFICIENCY IN  
CANCER CARE**

**PLUS:**

Stories from our  
international brain  
tumour community:  
USA, Canada,  
United Kingdom,  
Australia, Taiwan,  
Singapore,  
South Africa  
and many  
other countries

■ **LONG-TERM SURVIVAL  
IN GLIOBLASTOMA**  
an international study

■ **The SISAQOL  
initiative on  
analysing  
patient-reported  
outcomes and  
quality of life**

■ **DRUG DELIVERY  
IN CHILDREN  
WITH BRAIN  
TUMOURS**

■ **BRAIN TUMOUR  
NEWS AND DEVELOPMENTS  
FROM AROUND THE WORLD**





a project of the



## 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 2017**

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 (21 – 28 October 2017)** 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.



Top: The Braintrekkers walk in Hong Kong 2016

Above: The Brain Tumour Foundation of Canada Edmonton walk 2016

For more information please visit [www.theibta.org](http://www.theibta.org) or contact [chair@theibta.org](mailto:chair@theibta.org)

■ A brain tumour, a baby and a real-life fairy tale by Stefania Distante. .... 8	■ Heart over grey matter - the Brain Tumour Society (Singapore) brain tumour awareness campaign by Melissa Lim .... 43	■ Walking towards a cure for brain tumours . 83
■ Tackling brain tumours - cover story in <i>Cancer World</i> . .... 11	■ An interview with Professor Monika Hegi. . 46	■ Changing care needs for patients and caregivers by Dr Mary Lovely. .... 84
■ The 2016 WHO classification of tumors of the central nervous system by Professor David N Louis and Steven La Fond ..... 12	■ Step right up and meet the Amazing AN Warriors ..... 47	■ Brainstrust's superheroes don't fly. They walk ..... 86
■ Working together to foster better patient-centred cancer care (the SISAQOL initiative) by Kathy Oliver and Carmen Peuters ..... 14	■ I'm so proud to be able to help brain tumor patients and their families – an interview with Dr Jaap Reijneveld .... 48	■ SIMO...alla meta, SIMO...the goal. .... 88
■ Plugging the information gap in India by Dr Rakesh Jalali and Dr Raees Tonse. . 17	■ The CERN Foundation Outcomes Project by Alvina Acquaye ..... 50	■ I have a rare opportunity to make myself useful to others on my own life-changing journey by Laureline Gatellier ..... 90
■ Accelerating progress in drug delivery: Children's Brain Tumour Drug Delivery Consortium by Emma Campbell. .... 18	■ Residual issues: parking lot sympathy and sequelae by Bethany Kam ..... 52	■ Building bridges, not walls by Dr Alexandra Diaz Alba ..... 92
■ Long-term survival in glioblastoma by Professor Dr Michael Weller and Dr Caroline Happold ..... 20	■ Brain tumours in the Cayman Islands. .... 56	■ Running the Boston Marathon with neurofibromatosis by Anne Shigley Noble. . 94
■ The EANO palliative care task force by Dr Andrea Pace and Dr Martin Taphoorn. . 22	■ As a doctor with a brain tumor, I now truly appreciate the patient perspective by Dr Chris Chiou ..... 58	■ In memory of Paddy by the Holton Family . 98
■ Communication is key in brain tumor management by Dr Randall Porter. .... 24	■ I will survive: survivorship and brain cancer by Dr Danette Langbecker. .... 60	■ Patient reported outcome measures in neuro-oncological surgery by Dr Prajwal Ghimire. .... 101
■ New understanding of diffuse intrinsic pontine glioma (DIPG) provides real hope by Dr Mark W Kieran ..... 26	■ The Childhood Brain Tumor Association of Taiwan by Ying-Hsiu Lin ..... 64	■ I was a nurse for 40 years – but never understood the challenges of navigating a brain tumour until a family member was diagnosed with one by Catherine Hindson ..... 102
■ What's wrong with Shona? by Professor Willie Hamilton ..... 28	■ The Canadian Brain Tumour Registry Project ..... 66	■ Hjernesvulstforeningen: the Norwegian Brain Tumour Association. .... 104
■ Walk me home by Becky Livingston. .... 30	■ Brandon's inspiration helps ensure every brain tumour is counted in Canada by Jennifer Gouchie-Terris. .... 68	■ Caroline's legacy: the Peace of Mind Foundation, Australia ..... 106
■ The International Low Grade Glioma Registry enrolls its first 100 participants ..... 32	■ Driving and travelling after treatment for a brain tumour by Associate Professor Andrew Cole. .... 70	■ The PPR Foundation by Pamela Roberts . 110
■ Brain tumor survivor ran 7 marathons on 7 continents in 7 days by Nicola Beddow. . 34	■ The Pediatric Brain Tumor Foundation: in business to put brain tumors out of business by Robin Boettcher. .... 72	■ Meet Sean Leong, the new CEO of Cure Brain Cancer Foundation ..... 112
■ All.Can – striving for greater efficiency in cancer care. .... 36	■ Canine companions contribute significantly to brain tumor research. .... 74	■ The IBTA and European Federation of Neurological Associations ..... 114
■ A poignant Remembrance Day 2016 by Catherine Kloppe ..... 40	■ The little charity that could by Jennifer Egan ..... 78	■ It's Lovely down under by Dr Mary Lovely. . 116
■ Lunch is served – the Perth, Australia community marks International Brain Tumour Awareness Week ..... 42	■ Argentina: the Fifth Brain Tumour Awareness Day and First SNOLA Day by Dr Alejandra T Rabadán ..... 82	■ Japan Brain Tumor Alliance (JBTA) hosts a patient and family information exchange and study session in Tokyo by Hisato Tagawa and Laureline Gatellier. . 118
		■ Directory of brain tumour organisations and initiatives. .... 120



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### VARIATIONS IN SPELLING

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

## Dear Reader,

OUR eighth edition of *Brain Tumour* magazine continues to reflect the challenges encountered in our international brain tumour community every single day by patients, caregivers, medical and allied health care professionals, researchers, academics and those representing industry.

From the inspirational story of a young mother with a meningioma to understanding the new WHO classification of brain tumours to battling pediatric diffuse intrinsic pontine glioma to highlighting the crucial importance of national registries, *Brain Tumour* magazine focuses on a wide range of stories from around the globe.

Our coverage in this edition of *Brain Tumour* also extends to reports of awareness-raising activities, and interviews with medical professionals. There are articles about a study of long-term survival in glioblastoma, a new quality of life initiative, international efforts to achieve greater efficiency in cancer care, a recently-established palliative care task force for neuro-oncology and many other relevant topics.

But what ties all of these articles together – and indeed unites the entire world brain tumour community – is the determination we all have to significantly improve outcomes for people whose lives have been touched by this disease. And what binds us and steels us for the crucial job we face is our unwavering hope for a better tomorrow.



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.





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# About the International Brain Tumour Alliance (IBTA)

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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;

## HONOUR

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.

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# Our purpose, values and principles

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## Our purpose

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

## Values and principles

The IBTA's work is underpinned by the values of

- solidarity
- equity
- honesty
- integrity
- transparency
- hope

We are committed to strengthening the evidence base for patient-centred treatment and care, in particular through the telling of and promoting of peoples' experiences and perspectives.

# Meet the IBTA team



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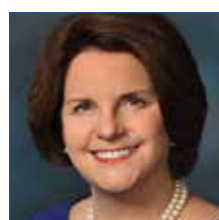
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# A brain tumour, a baby and a real-life fairy tale

Stefania Distante

Cheltenham, United Kingdom

MY story is like a fairy tale, albeit one including a brain tumour and fertility problems. I was planning my wedding when from one day to the next, life as I knew it ended and a new life began.

My fiancé and I were in Italy to exchange pre-wedding vows following an Italian tradition called 'The Promise'. My father, a retired doctor, arranged for me to have a brain MRI on the same day. This was purely to put his mind at rest after some symptoms I had discussed with him.

When he told me they found a brain tumour, he was shaking. I was 30 years old and had so many plans for my life.

I had two questions for him: "Is it cancer?" and "Can I have children?" He didn't know the answer to either at this early stage.

## An emotional wedding vow takes on a new meaning

We went right from the hospital to the church to read our vows: "In sickness and in health." We knew this would cement our relationship: walking together into the unknown. Later that day we told my mum. This was the most heart-wrenching part of my diagnosis, seeing her break down with fear and hurt, wishing she had the tumour instead of me.

Returning to our home in the United Kingdom meant finding a neurosurgeon who could help me and answer my questions. I was seen by neurosurgeon Mr David Porter who was to become one of the most important men in my life. When I met him I had a sense of total calm and peace, I knew he was going to be the man who would save me.



Above: Our beautiful daughter, Gaia, sleeping, age eleven weeks



Above: My perfect wedding day as I started married life with my husband

"Is it cancer?" I asked.

"It appears to be a meningioma. But a biopsy after surgery will confirm this" he said.

"Can I have children?" I asked.

"You probably could but you may not wish to" Mr Porter said. I didn't really understand what he meant by this.

I needed to find other people like me, to meet brain tumour survivors, to understand what lay ahead. Hours of Internet searching left me more scared than reassured. I was lucky enough to find two charities that provided initial support.

The first was an American charity called 'Meningioma Mommas' which provides an online support network. The second was a British charity, called Brain Tumour Support (<http://www.braintumoursupport.co.uk>), which runs support group meetings. Both held my hand, as I had booked a date for surgery six weeks after our wedding.

I asked my family to keep my brain tumour a secret. We wanted to enjoy our wedding day and not have our guests worry or, worse still, feel sorry for us. Our wedding was a celebration of our love, our lives and our future together, no matter what.



**Top:** Mr Porter, my neurosurgeon, some weeks after my surgery to remove a meningioma



**Above:** On Gaia's first birthday at the zoo

### 31st August 2006, 7.00 am

I was wheeled to theatre [the operating room] on a hospital bed with my family and husband close to me. The surgery was a success. I spent five days in hospital and then began a very long recovery at home.

Tiredness and exhaustion do not begin to describe the level of mental and physical fatigue after brain surgery. I was in a world of my own, sleeping for 18 hours a day and becoming unbelievably tired, even after only a five-minute conversation with my husband. Months passed by with little improvement. It dawned on me that recovery was a slow and very long journey. Was Mr Porter right? Would I choose not to have children? How could I possibly cope?

Life as I knew it ended. I could not return to what I was doing before the 31st of August. I had to readjust almost every aspect of my life to reach a happy compromise with the 'new me'. I had been saved from a life threatening tumour and now I had to live my life!

### Would starting a family be possible?

After years of recovery I was left with neurological damage causing mental fatigue and chronic migraines. I lost my career. I could not return to work. I had to find ways to feel my sense of worth again, to redefine myself.



**Above:** I spoke about my brain tumour and pregnancy journey at the 2016 European Society for Medical Oncology (ESMO) patient advocacy track. Gaia and I are standing in front of the conference centre in Copenhagen, Denmark. It was Gaia's first medical conference too!

How could I face starting a family? I was exhausted enough by doing very little and by being on my own. The prospect of bringing a new life into the world was absurd.

Through counselling, 'mindful meditation' and support from the Brain Tumour Support charity I began to rebuild myself.

I accepted the loss of career. I accepted the loss of health. I took up photography and volunteered for local charities. Both interests helped me regain a sense of self-worth.

Whilst I achieved a balance between daily activities and exhaustion levels I was still not at peace. I always felt very maternal and took it for granted that one day I would be a mum.

The fear of the unknown and of not being able to cope was stopping me from living the life I wanted. I had to either abandon the dream of becoming a mother or head into the unknown. ➤





Above: Volunteering for Brain Tumour Support and selling calendars I created to raise funds for the charity. For more information on Brain Tumour Support see [www.braintumoursupport.co.uk](http://www.braintumoursupport.co.uk)

After years of deliberation and discussion, my husband and I decided that we would not give up on our wish to have a family. Three years on we were still without a child.

We sought medical help and were told that it would be impossible for us to conceive and that the only alternative was in vitro fertilisation (IVF). This involved significant hormonal therapy which could trigger a brain tumour recurrence.

I got in touch with my neurosurgeon and a nurse practitioner in neuro-oncology from The Netherlands, Hanneke Zwinkels, who had done some research into brain tumours and pregnancy. They both advised me that the risk of recurrence was small and I should not give up on having a family. I trusted them and underwent IVF treatment. Thankfully I became pregnant on the first cycle. My miraculous baby girl was born on my birthday. Three months post birth my follow-up MRI was scheduled and showed a clear result: no recurrence!

After a ten year journey I was tumour free and had a baby girl: this is a real life fairy tale.

### Motherhood and me

Sometimes in life we need to follow our instincts and desires. I weighed up the risk of tumour recurrence against the agony of not having a family. I was prepared to take that risk.

Although I still suffer with chronic migraines and mental fatigue, the joy which having a child has given me dwarfs the pain I feel. It is the most challenging role I have undertaken and at the same time the most fulfilling.

The help and support I received from medical professionals and charities has been invaluable. I have immense respect for the teams of doctors and nurses who helped me.



Above: Gaia and me on my first-ever Mothering Sunday (Mother's Day)

I realise I have been truly blessed in this life. Without the brain tumour I am not sure I would know what true happiness is.

I will teach my daughter that life is precious and challenges can make us stronger. If we really desire something with all of our hearts, we can find a way of making it happen, we can overcome obstacles.

The important thing is to try, to live the life we want, without regrets, and with love. ■



# Tackling brain tumours – cover story in *Cancer World* magazine

Don't miss journalist Peter McIntyre's focus on the people determined to beat brain tumours



IN their 3rd March 2017 issue, *Cancer World* magazine talked to some of the doctors who lead the collaborative academic

research networks that drive progress in brain cancers, to hear about their hopes, their frustrations and how the energy from their patients fuels their determination to find more effective treatments.

Featured in the article are: EORTC Director General Denis Lacombe; EORTC President Professor and neuro-oncologist Roger

Stupp; Chairman of the Department of Neurology, University Hospital Zurich and Chair of the EORTC Brain Tumour Group Professor Michael Weller; Head of the Neuro-Oncology Unit at Erasmus MC Cancer Center Professor Martin van den Bent; Head of the Department of Radiation Oncology at MediClin Robert-Janker Clinic in Bonn Brigitta Baumert and the IBTA's Kathy Oliver.

The article is free access and can be read online. See right for details.

*Cancer World* magazine – published six times a year by the European School of Oncology – is where the voices of healthcare providers, researchers, patient advocates and policy makers come together to discuss how to improve the quality of care delivered to patients

everywhere. *Cancer World* explores the complexity of cancer care from all these very different viewpoints, and offers readers insight into the myriad decisions that shape their professional and personal world.

*Cancer World* is distributed at major conferences and mailed to subscribers and to European opinion leaders. ■

View *Cancer World's* cover article on brain tumours here:

<http://bit.ly/2mAlWph>

You can subscribe to the online edition of *Cancer World* at <http://bit.ly/CW-online> or sign up for the free print version at <http://bit.ly/CW-print>



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**5<sup>TH</sup> QUADRENNIAL MEETING**

Photo © Zurich Tourism

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# The 2016 World Health Organization Classification of Tumors of the Central Nervous System

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## Introduction

In the summer of 2016, the World Health Organization (WHO) published an updated classification of central nervous system tumors, setting a new standard for brain tumor research and communication between different centers around the world.

The revised fourth edition is a major update to the existing 2007 WHO classification and brings the naming and grouping of brain tumors into line with current scientific understanding and technology. For the first time, the new WHO classification combines genetic information about brain tumors with their histology, thereby formulating a more accurate concept for how brain tumor diagnoses should be described and structured.

This new classification is the culmination of work by 117 experts from 20 countries and will allow for more accurate diagnosis, treatment planning and prognosis. With the new classification, brain tumor patients in clinical trials may be stratified into groups that reflect the particular molecular profile of their tumor, allowing suitable targeted treatments to be used in a hopefully effective way. The new classification will also aid researchers by helping them to make more precise analyses of data in the lab, and to accurately compare their results with other institutions.

The IBTA is excited by the publication of the new classification and recognises that it represents a significant step forward in the ongoing challenge to improve outcomes for brain tumor patients. The IBTA also extends its gratitude to the many

international experts whose hard work has brought about the updated classification, which will serve to benefit brain tumor patients around the world.

## With thanks...

We are indebted to US pathologist Professor David N Louis of Massachusetts General Hospital and Harvard Medical School - who was the lead editor of the WHO classification - and his numerous colleagues who contributed to this work.

Under the auspices of the National Brain Tumor Society (NBTS), Dr Louis recorded two short videos, explaining in layman's language what the new classification means to brain tumor patients and their families.

The IBTA is grateful to NBTS for allowing us to reproduce portions of the transcript of Dr Louis' videos in this year's edition of *Brain Tumour* magazine.

Additional thanks to Steven LaFond at NBTS for interviewing Dr Louis and for his help with creating the transcripts of these videos which form the basis of this article.



Above: Professor David N Louis, lead editor for the 2016 WHO classification of central nervous system tumors

## NBTS: Why do we do brain tumor classifications in the first place?

**Dr. Louis:** Tumor classifications are done for many reasons. They range from helping individual patients manage their diseases, to helping studies get done (for example clinical trials or experimental studies involving cells or animals). They help epidemiologists and governments to figure out what causes disease. By classifying the disease you can study it and then find out what causes it and then devote resources by governments or by insurance companies to addressing the health care needs of patients with those diseases.

For about a hundred years, tumors

were classified by pathologists looking under the microscope at small pieces of tumor given to them by the surgeons. The pathologists could stain the tumor in different ways, but the bottom line is that they were looking under a microscope and coming up with a pattern, and that pattern was then matched to a pattern's name in a classification.

## NBTS: Why did the World Health Organization decide to revisit the classification?

**Dr. Louis:** The whole field of pathology and cancer medicine in general has undergone a revolution over the last two

decades since we now know a lot of the genetic underpinnings of tumors. And those genetic underpinnings are changing the way we think about classifying them, but also the way we think about treating the patients who have the different types of tumors.

So, it was clear to the field at large that we needed to think about this beyond simply the microscope. In 2014 in Haarlem in The Netherlands we put together a group of leading people in the field of CNS tumor classification and the meeting published its guidelines. Asking whether the field of CNS tumor classification was ready yet to do what the hematologic cancers had done a few years earlier, the meeting participants answered with a resounding “Yes, let’s go ahead and do it,” with some caveats that it had to be done in a careful, deliberative way.

#### **NBTS: What are the major changes to the brain tumor classification?**

**Dr. Louis:** The major takeaway is that the diagnosis of many CNS tumors, but not all CNS tumors, will not only be based on the microscope but on the microscope plus genetic analysis. For example, if you’re talking about adult brain tumors, glioblastoma is one that now gets a genetic analysis in addition to the microscope analysis.

#### **NBTS: How will the new WHO classification impact brain tumor patients?**

**Dr. Louis:** Patients will be getting more specific diagnoses on their tumors if they are the kinds of tumors for which we have incorporated molecular parameters into classification. But there are many, many tumors that will be classified the same in 2016 as they were in 2007.

#### **NBTS: Will be there any changes to the way a brain tumor is diagnosed?**

**Dr. Louis:** The difference is that the diagnostic reports will come out in layers, but also in stages. So, one thing that patients are going to have to be aware of is that if they have one of the tumors for which we do genetic analysis, the full diagnosis may be delayed for a few weeks. They’ll get the same diagnosis that they’ve always gotten within a week based on using the microscope, but the full diagnosis (what we call the integrated diagnosis) will need to

wait, in a few situations, for a few weeks.

The good news is that patients are getting a more precise diagnosis, but the bad news is that the precise diagnosis - at least because of the technical challenges of the present time with doing these tests - may require a couple more weeks. For most brain tumor patients that shouldn’t be a problem, because most patients are waiting for their surgery sites to heal before going ahead with their treatments.

#### **NBTS: How will the new WHO classification impact brain tumor patients diagnosed before the updated tumor types?**

**Dr. Louis:** The types of tests that we do can be done on existing materials. So, if a patient discusses that exact question with his or her physician, and they together decide it would be important to go back and do the analysis, then we can go ahead and do that if sufficient tissue remains in their specimens.

In other words, we can do it retroactively, but it’s a question for individual patients and their oncologists to decide whether it needs to be done. There are certain times where the importance of it may be more related to what happens on individual treatment, and others where that may not be true. For this reason, it is up to individual patients and their oncologists to decide. ■

These videos can be viewed on YouTube here: <https://www.youtube.com/watch?v=ys5Brmg39oc> (Part 1 which is an introduction to the new classification) and here: [https://www.youtube.com/watch?annotation\\_id=annotation\\_3778688259&feature=iv&src\\_vid=ys5Brmg39oc&v=CoHKxuxw0yc](https://www.youtube.com/watch?annotation_id=annotation_3778688259&feature=iv&src_vid=ys5Brmg39oc&v=CoHKxuxw0yc) (Part 2 which is a more detailed look at the classification).



## *Braintrekking 2016*

Dr Danny Chan wrote to the IBTA to say that “Braintrekking 2016” - organized by the Chinese University of Hong Kong Otto Wong Brain Tumour Centre - was held at the Peak of Hong Kong on 23rd April. This was the ninth Hong Kong Walk Around the World for Brain Tumours. Dr Chan said: “Braintrekkers are used to the changing April weather in Hong Kong. And they were all determined to climb to the Peak be it a rainy or stormy day. We had a record-breaking 458 trekkers (450 people and eight dogs) completing the 3.5km trail at the Peak of Hong Kong and, as it turned out, it was a dry Saturday morning.” Braintrekking collected 1603 km to donate to the IBTA’s global “Walk Around the World for Brain Tumours”. ■



# Working together to foster better patient-centred cancer care

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

Kathy Oliver, International Brain Tumour Alliance and Carmen Peuters, EORTC on behalf of the SISAQOL Consortium\*

\*The members of the Consortium are named in the reference on page 16.



Above: Attendees of the SISAQOL Consortium meeting held in Amsterdam in January 2017.

A patient's health-related quality of life during treatment and in the long-term is important. Cancer patients and their families are not only concerned about a cure, but also about the symptoms (e.g. pain, fatigue) and other physical and emotional consequences that come along with the disease and treatment, impacting the daily life of the patient. It is therefore essential that these health aspects are taken into account when evaluating any new therapies. Questionnaires to measure health-related quality of life are increasingly being used throughout cancer research. Patients devote their time to completing these questionnaires, but often it is unclear how the responses are analysed and reported. Thanks to the input from and collaboration with patients, the Setting International Standards in Analysing Patient-Reported Outcomes and Quality of Life Endpoints Data (SISAQOL) project might offer a solution.

## SISAQOL

The Setting International Standards in Analysing Patient-Reported Outcomes and Quality of Life Endpoints Data (SISAQOL) initiative

has been established to create consistency in the analysis and reporting of patient-reported data in cancer clinical trials. An international, multidisciplinary Consortium was assembled by the European Organisation for Research and Treatment of Cancer (EORTC). Not only were leading statisticians and researchers from various disciplines including psychology and medicine involved, but also key individuals from various international oncological and medical societies; advisory and regulatory bodies; academic societies; the bio-pharmaceutical industry; cancer institutes; and, crucially, patient advocacy organisations, including brain tumour patient advocates. They are now all working together to develop guidelines for the analysis and interpretation of health-related quality of life and other patient-reported outcome data in cancer research.

## What are health-related quality of life and other patient-reported outcomes?

A patient-reported outcome refers to any report about a patient's health condition that comes directly from the patient, without the interpretation of the patient's response by anyone

else. Health-related quality of life is a type of patient-reported outcome which focuses on how a patient feels and functions in relation to their disease. It is dynamic (it changes over time), multidimensional (it captures several aspects such as physical, social and emotional functioning that are related to the disease and treatment) and subjective (it is reported from the perspective of the patient). The most common way to gather health-related quality of life and other patient-reported outcome data is through the use of scientifically validated questionnaires.

In the 1990s, health-related quality of life was still a new concept and questionnaires were available in only a few languages and for only a few disease types. In those days, there was some scepticism and debate among investigators about how health-related quality of life outcomes in cancer clinical trials should be interpreted alongside other trial outcomes such as tumour response and overall survival. Because only a few studies worldwide included health-related quality of life and other patient-reported outcomes, there was little evidence yet of its added value for the development and evaluation of cancer therapies.

In the years since, health-related quality of life has found its way into cancer clinical trials and has become increasingly important in understanding the effects of the disease and treatment on individual well-being. A growing number of questionnaires assessing the benefits and risks of cancer therapies have been developed and are now available in numerous languages and in a wide range of disease-specific modules (e.g. a questionnaire aimed specifically at brain tumour patients and so covering the most important problems regarding brain tumours). Health-related quality of life is no longer a new concept for clinical groups. It has now been generally accepted and shown by many studies worldwide that findings from health-related quality of life and other patient-reported outcomes can help inform cancer research, regulatory decision-making, and clinical practice.

### The patient's voice

The inclusion of patient-reported outcomes into cancer clinical trials is highly meaningful to cancer patients. By reporting on their current levels of functioning (e.g. physical, social and emotional) and the side effects of a treatment, the patient's voice can be documented and taken into account in the development of new therapies. The results from patient-reported outcomes allow future patients to be better informed on the implications and consequences of a treatment, thus helping them make a decision on which treatment to commence. Information from patients can even help new therapies come to the market, hence improving access to needed therapies by future patients.

### The need for guidance

The data gathered on health-related quality of life provide rich information. For example, a patient can be extremely fatigued during the first weeks of an intensive treatment but return to a normal level of energy when approaching the end of the treatment, while at the same time the burden from a specific symptom such as neuropathic pain may be limited at the beginning of the treatment but get worse as treatment

progresses. Health-related quality of life data therefore are more complex than survival outcome data, and there are many ways in which one can evaluate health-related quality of life as a treatment outcome. The problem nowadays is that standards on how to analyse and interpret those data are still missing, and as long as there are no set principles, it becomes difficult to assess the value of the findings, compare findings across trials and ensure reproducibility of the results. The aim of SISAQOL is to develop guidelines for the standardisation of the analysis of health-related quality of life and other patient-reported outcome data, which will ultimately help facilitate clearer communication of the obtained findings between patients, clinicians, researchers and other stakeholders.

### When answers are missing

In order to get a more accurate representation of the patient's experience during cancer treatment, it is critical that the questionnaires are filled in as completely and truthfully as possible. All questions that are not answered must be treated by researchers as missing data, and a high percentage of missing data will make it difficult to analyse patients' responses in the most appropriate and effective way.

For various reasons, however, the questionnaires to assess health-related quality of life in a cancer study are not always completed. Occasionally, certain questions that might be relevant, such as issues of sexual functioning, may be considered too sensitive by some patients; or, patients may just be too sick to respond. Moreover, there are often operational barriers that hinder patients from completing the measures. Hospitals are facing increased pressure to deliver more and better patient-centred care, and including a series of patient-reported outcome measures for all patients adds another layer of complexity and burden to the hospital system and hard-working staff, preventing for example the doctors or nurses from providing patients with the relevant measures at the critical time.

It will therefore be essential for SISAQOL to work together with patients, hospital and clinic staff, and research teams, to explain the importance of obtaining completed measures of health-related quality of life and other patient-reported outcomes. If, for example, all informed consent forms could have statements that stress the value of quality of life data, perhaps this could serve as a motivation for the patients to comply with the measures. Also, patient advocacy groups could encourage hospitals and other health care providers to invest in infrastructure and resources in order to prioritise the collection of patient-reported outcomes. Such initiatives could help overcome some of the major challenges in health-related quality of life research. In addition, the SISAQOL initiative will research best practice methods to help analyse clinical studies that do have missing patient-reported outcome data.

### Together towards a solution

The SISAQOL project can make a real difference in the lives of cancer patients, including those with brain tumours. As stated in the first SISAQOL publication in *The Lancet Oncology*: "in the interest of improving their situations and helping others, ➤

[patients] voluntarily give up their time to complete measures for these trials. Therefore, the data we gather must be exploited to the full, with statistical analyses done in the most rigorous and standardised way, and with results that clearly highlight clinical benefits and not just statistical significance" (Bottomley et al., 2016, p.4, see reference at right). The SISAQOL project will help clinicians and patients make better sense of the numbers and make research findings more understandable for them. The establishment of the SISAQOL Consortium encourages patients, researchers, clinicians, and other stakeholders to all work together with the aim of improving patient-centred cancer care. ■



Left: IBTA Chair Kathy Oliver addressing the SISAQOL Consortium meeting held in Amsterdam in January 2017.

#### Acknowledgments

SISAQOL has received an unrestricted educational grant from Boehringer Ingelheim GmbH to undertake this work. The SISAQOL Consortium's views should not be construed to represent any official views of the policies of the US Food and Drug Administration (FDA), US National Cancer Institute (NCI), Medicines and Healthcare products Regulatory Agency (MHRA), The Institute for Quality and Efficiency in Healthcare (IQWiG), or Health Canada.

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# Plugging the information gap in India

Brain tumour booklet translated into various local languages helps patients and caregivers better understand their disease

Rakesh Jalali\*, KV Ganpathy# and Raees Tonse\*

On behalf of Brain Tumour Foundation of India\* and JASCAP#



Above: Some of the languages into which a booklet for patients and caregivers on all aspects of brain tumours and its management has been translated.

India is a country of diverse cultures, and people speaking different languages are scattered throughout the country. It has been estimated that there are as many as 880 languages and dialects spoken across India. Out of them, 22 languages have been recognised by the constitution of India as the most commonly spoken in different parts of the country.

The Brain Tumour Foundation of India (BTF) along with JASCAP (JEEET Association for Support to Cancer Patients) - a well recognised knowledge-based non-governmental organisation - jointly launched an initiative in March 2015 to translate information on brain tumours into as many languages as possible.

A booklet with all relevant information from patients and caregivers' perspectives, written in a simple easy-to-understand manner and peer-reviewed by clinicians, patient representatives and social workers was initially published in English. The booklet captures information on all aspects of brain tumours and their management with the intention to create awareness and education.

With such a diverse population and varying literacy rates in India, the objective

is to get the booklets translated into other major Indian languages. With this aim the first booklet in English and Malayalam (the official language of Kerala State and one of the major languages of South India) was launched at the 7th Annual Indian Society of Neuro Oncology (ISNO) conference in March 2015 held in Kochi, Kerala.

The booklet has been subsequently translated after due rigour into four more languages:

**Hindi** (India's national and most commonly spoken language)

**Marathi** (mainly spoken in Maharashtra and Western India)

**Telugu** (South India) and

**Bengali** (major language in Eastern India and Bangladesh)

The **Kannada** (mainly in Karnataka in South India) translated version was launched at the 9th Annual ISNO conference in March 2017 in Bangalore. Three more languages (**Punjabi**, **Tamil** and **Oriya**) are in different stages of translations at the moment and likely to be launched in the next few months.

Each booklet is attractively priced at Rs 50 (US \$0.75). BTF is also supporting distribution of several thousand booklets

to various centres throughout the country free of charge. It is hoped that the translated booklets will help address the information gaps in India, given its diverse cultural and literacy landscape. We aim to get translations done in all 22 major languages in due course. ■

The IBTA maintains a list of key online clinical trials portals to help patients and caregivers locate clinical trial centres and understand criteria for joining a brain tumour trial. For more information, visit [www.theibta.org](http://www.theibta.org)

# Accelerating progress in drug delivery: Children's Brain Tumour Drug Delivery Consortium

Emma Campbell, Children's Brain Tumour Research Centre

Nottingham, United Kingdom

On behalf of the Children's Brain Tumour Drug Delivery Consortium (CBTDDC)



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

LAST year, we wrote an article in the IBTA's *Brain Tumour* magazine summarising the highlights from a pioneering workshop held in London in February 2016. Initiated and funded by the charity Children with Cancer UK, this workshop was dedicated to drug delivery in the treatment of paediatric brain tumours.

The dedication and passion of delegates shone through as they discussed different experimental techniques aimed at optimising drug delivery in children's brain tumours (1,2). We all left the workshop buzzing with enthusiasm, hopeful that what has been a neglected topic would now receive the attention it needs. Children with Cancer UK, determined not to let the momentum wane, was quick to open a GBP £1.2 million funding call to support projects related to the workshop. They 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 consortium to raise awareness and promote collaboration in the field.

Welcome to the Children's Brain Tumour Drug Delivery Consortium (CBTDDC)! We are delighted that our funding application

was successful and, under the leadership of Professor David Walker, have big plans, ambitions and hopes for the next two years.

Children's brain tumours account for around 20% of childhood cancers in Europe. Around 4,800 cases are diagnosed each year in the US, and 30,000 - 40,000 per year worldwide.

Brain tumours are also the leading cause of cancer-related death in children and young adults in developed countries. Furthermore, damage to the developing child's brain means that two thirds of those cured will be disabled for the rest of their lives.

A major challenge to improving this outcome, is to ensure treatment is delivered to the tumour, across the blood brain barrier (BBB), at therapeutic and non-toxic concentrations for a long enough time period to achieve the desired effect.

The CBTDDC is tasked with bringing together world-leading experts to take on this challenge, by exploring the use of novel drug delivery systems to physically bypass the BBB.

Professor David Walker, Chair of the consortium, said: "This consortium was born from a strong need for sharing knowledge and expertise within the area of childhood brain tumour drug delivery, in order to make significant headway in this challenging area.

"This will be the first time that there has ever been global coordination of a paediatric brain tumour drug delivery consortium, offering unrivalled opportunities for open dialogue and sharing of resources, which in turn will accelerate translational research in this area."

The consortium will organise and host discussions of an international, multi-

disciplinary network of clinicians and researchers committed to developing drug delivery systems applicable to children with brain tumours.

Through raising awareness and sharing expertise with a range of stakeholders, it will be uniquely placed to strengthen collaborative developments in the field of drug delivery by working closely with the international brain tumour community and its funders.

The consortium's network of experts, initially from eight institutions across North America and Europe (see sidebar, page 19), will promote a more joined-up approach to assessing whether innovative new drug delivery methods, and those that have been successfully used to treat other types of cancer, could become a new avenue for tackling childhood brain tumours.

The consortium will also highlight the importance of the field to funders, industry and regulators, while working closely with patient and carer charities and not-for-profits to ensure the priorities and perspectives of patients are strongly represented.

The consortium launched at the beginning of March, at the ACCELERATE Paediatric Oncology Conference 2017 in Brussels, Belgium. This conference was a perfect fit for the consortium, focussing on discussing strategies to accelerate new oncology drug development for children and adolescents. You can read the highlights of our launch at ACCELERATE in the box on page 19.

In essence, the Children's Brain Tumour Drug Delivery Consortium echoes the IBTA's strapline of 'Greater Collaboration, Greater Knowledge, Greater Hope'. Please do get in touch if you are interested in networking in this area, or would like to be kept in the loop with regards to our activities. ■

<sup>1</sup> Nailor, A, Walker, DA et al, 2016. Highlights of Children with Cancer UK's Workshop on Drug Delivery in Paediatric Brain Tumours, eCancer. 10, 630.

<sup>2</sup> <http://ecancer.org/conference/831-drug-delivery-in-paediatric-brain-tumours.php>

## The ACCELERATE Paediatric Oncology Conference 2017



**Above:** The nine members of the Children's Brain Tumour Drug Delivery Consortium (CBTDDC) who attended the ACCELERATE Paediatric Oncology Conference 2017 in Brussels, Belgium. Pictured from left to right are: Ruman Rahman, Gareth Veal, Dannis van Vuurden, Marie Boyd, Emma Campbell, Richard Grundy, Darren Hargrave, Steven Powell, David Walker.

On 2 - 3 March 2017, nine members of the Children's Brain Tumour Drug Delivery Consortium (CBTDDC) attended the ACCELERATE Paediatric Oncology Conference 2017 in Brussels, Belgium. Armed with CBTDDC logo stickers and leaflets, we immersed ourselves among the 134 delegates to raise awareness of this new initiative and to foster new relationships and collaborations.

The conference was well-attended by a range of stakeholder groups, including pharmaceutical companies, regulatory bodies, patient groups, charities, academics and clinicians. We spoke with individuals from each of these groups, and our *raison d'être* and ambitious plans were met with support and encouragement.

Interestingly, several speakers described emerging consortia and platforms, each tasked with facilitating greater collaboration between certain groups of stakeholders. It was particularly rewarding to share our plans with these colleagues, and to discuss ways in which we could work together going forwards.

We were also delighted to speak with patient representatives, and hope to bring individuals into the Steering Group soon so that there is full representation from patients and caregivers.

More than anything, ACCELERATE reinforced our belief that the time is right to push forward with the CBTDDC. We will capitalise on this momentum and enthusiasm, joining with others in this movement towards greater collaboration for the benefit of children with brain tumours.

## Consortium Steering Group

**Consortium Project Manager**  
**Emma Campbell**  
The University of Nottingham, UK

**Steering Group Members**  
**David Walker**  
The University of Nottingham, UK  
**Richard Grundy**  
The University of Nottingham, UK  
**Ruman Rahman**  
The University of Nottingham, UK  
**Henry Brem**  
Johns Hopkins University, US  
**Monica Pearl**  
Johns Hopkins University, US  
**Jordan Green**  
Johns Hopkins University, US  
**Miroslaw Janowski**  
Johns Hopkins University, US  
**Kenneth Cohen**  
Johns Hopkins University, US  
**Piotr Walczak**  
Johns Hopkins University, US  
**Katherine Warren**  
National Cancer Institute, US  
**Stephen Lewis**  
Bristol Royal Hospital for Children, UK  
**Alexander Mullen**  
University of Strathclyde, UK  
**Marie Boyd**  
University of Strathclyde, UK  
**Gareth Veal**  
Newcastle University, UK  
**Darren Hargrave**  
UCL Institute of Child Health, UK  
**Dannis van Vuurden**  
VU University Medical Center, Amsterdam  
**Steven Powell**  
Fast Track Pharma Limited, and Macrophage Pharma Limited, UK  
**Patient and caregiver representatives**  
To be appointed

For further information about the Children's Brain Tumour Drug Delivery Consortium, please register your interest at [www.cbtdc.org](http://www.cbtdc.org)



# Long-term survival in glioblastoma

Professor Dr Michael Weller and Dr Caroline Happold

Zurich, Switzerland, for the EORTC 1419 study team

GLIOBLASTOMAS are malignant primary brain tumors and range amongst the most lethal cancer types in adults. They account for almost 50% of all brain tumors in adults, affecting three out of 100,000 patients per year, mostly in the later period of life.

Glioblastomas invade the brain by infiltration, thus leading to significant destruction of healthy tissue and consequently neurological symptoms, including considerable loss of quality of life. This aggressive tumor also leads to a significantly shortened survival, and unfortunately, almost half of the patients diagnosed with glioblastoma pass away in the first year of diagnosis.

The use of a multimodal therapeutic approach, involving surgery, radiotherapy and a variety of chemotherapeutic agents aims at prolonging overall survival, but often only increases life span for a few additional months. Yet, a small percentage of up to 5% of all patients suffering from glioblastoma may survive for more than five years. These are often, but not exclusively, younger patients with gross total tumor resection, whose tumors exhibit some prognostically favorable molecular features, such as mutations of isocitrate dehydrogenase (IDH) or methylation of the O6-methylguanine DNA methyltransferase (MGMT) promoter. This subgroup of patients is referred to as long-term survivors. However, other determinants of long-term survival have yet to be identified.

To determine a maximum of factors that might influence long-term survival in glioblastoma patients is the goal of a large international multicenter study generously supported with USD \$2,000,000 by the Brain Tumor Funders' Collaborative, a strategic partnership among private philanthropic and advocacy organizations in the US and Canada composed of five members:



Above: Prof Dr Michael Weller, Department of Neurology, University Hospital Zurich, Switzerland

- American Brain Tumor Association
- Brain Tumour Foundation of Canada
- Children's Brain Tumor Foundation
- James S. McDonnell Foundation
- Sontag Foundation

The study is conducted under the lead of the Brain Tumor Group of the European Organisation for Research and Treatment of Cancer (EORTC) in Brussels, Belgium, and the Brain Tumor Center at the University Hospital Zurich, Switzerland.

A consortium of more than 20 sites in Europe, the United States and Australia is currently registering patients with a survival of more than five years from glioblastoma diagnosis to a large comprehensive database, collecting clinical disease characteristics including all information on tumor therapy and follow-up, as well as imaging data. First results of the clinical and histological analysis have recently been presented at the annual meeting of the Society for Neuro-Oncology (SNO), and several additional sites have asked to participate in this study since then, underlining the relevance and interest in the attempt to understand the course of this disease.



Above: Dr Caroline Happold, Department of Neurology, University Hospital Zurich, Switzerland

To date, more than 150 patients, alive and deceased, have been registered to the EORTC database, and the long-term survivors identified so far are overall of younger age, with a median age below 50 years. More than half of all patients were alive at the time of registration. Therefore, assessment of the total numbers of chemotherapeutic courses, surgeries at recurrence, or overall radiation doses in the course of the disease, as well as follow-up imaging data - which is collected in a separate platform and analyzed for tumor growth and recurrence pattern by different imaging tools - are still ongoing.

All registered patients receive a mandatory central review of the pathological diagnosis, confirming the histology on one hand, and allowing for further molecular analysis and biomarker information on the other hand. In the currently analyzed tissue sample set, MGMT promoter methylation already emerges as a significant parameter, with most of the investigated tumor samples exhibiting methylated MGMT promoter. The analysis of other molecular markers is ongoing.

In a second step, the acquired information is later compared to a

matched data set of a reference cohort of glioblastoma patients with an overall survival of less than five years.

To further assess the relevant issues of quality of life and neurocognitive status in patients surviving glioblastoma more than five years, the patients who are alive at the time of registration participate in several follow-up assessments of their health and mood, their quality of life and a battery of neurocognitive tests. Currently, more than 50 patients participate in this project, which is more than initially anticipated, underlining the relevance for both medical teams and patients to support this specific question despite the time-consuming examination.

Most living patients additionally contribute blood samples at each consultation. These blood donations are investigated in several projects: one addresses the role of immunological factors potentially involved in long-term survival, a sub-project performed in Zurich. The results could help to understand the role

that the patient's immune system plays in tumor formation and tumor control, possibly allowing for specific treatments in the future.

Other samples are characterized for detailed proteomics analyses, a large-scale study of proteins, to identify specific patterns in the long-term survivor collective. Finally, some blood samples are processed for full sequencing of the whole genome, a very detailed and comprehensive approach to determine DNA singularities in this specific patient group. The first results of these broad analyses are expected this year (2017).

The knowledge gained with this ongoing study should hopefully contribute to a better understanding of the overall development of glioblastoma. The comprehensive characterization of the molecular and physiological determinants of long-term survival could eventually help develop an optimized treatment strategy for each glioblastoma patient in the future by modulation of the identified parameters involved in long-term survival. ■

**EORTC 1419 is open  
for patient registration.**

**Questions regarding  
participation can be  
addressed to**

**Caroline.Happold@usz.ch**

**Plan your 2017 "Walk  
Around the World for  
Brain Tumours" now!**

**For further information contact  
chair@theibta.org**

### **Study centers for the EORTC 1419 trial:**

#### **Molecular genetic, host-derived and clinical determinants of long-term survival in glioblastoma**

#### **EUROPE**

Amsterdam, The Netherlands	Jaap C Reijneveld	Department of Neurology, VU University Amsterdam
Athens, Greece	Evangelia Razis	3rd Oncology Department, Hygeia Hospital
Bonn, Germany	Ulrich Herrlinger	Division of Clinical Neurooncology, Department of Neurology, University of Bonn
Brussels, Belgium	Florence Lefranc	Department of Neurosurgery, University Hospital Brussels
Dresden, Germany	Gabriele Schackert/Dietmar Krex	Department of Neurosurgery, University of Dresden
Essen, Germany	Martin Glas	Department of Neurology and Neuro-Oncology, University Hospital Essen
Freiburg, Germany	Oliver Schnell	Department of Neurosurgery, University of Freiburg
Heidelberg, Germany	Wolfgang Wick	Department of Neurooncology, National Center for Tumor Diseases and Neurology Clinic, University of Heidelberg
Lyon, France	Francois Ducray	Lyon Neuroscience Research Center INSERM, University of Lyon, and Department of Neuro-Oncology Université Claude Bernard Lyon et Groupe Hospitaliere Est
Munich, Germany	Jörg C Tonn	Department of Neurosurgery, University of Munich
Paris, France	Antoine Carpentier	Department of Neurology, Hospital Avicenne,
Regensburg, Germany	Peter Hau	Department of Neurology, University Hospital Regensburg
Torino, Italy	Riccardo Soffietti	Department of Neuro-Oncology, University Hospital Turin
Vienna, Austria	Christine Marosi	Department of Oncology, Medical University of Vienna
Zurich, Switzerland	Michael Weller	Department of Neurology and Brain Tumor Center, University Hospital Zurich

#### **UNITED STATES**

Boston, Massachusetts	David Reardon/Patrick Wen	Center for Neuro-Oncology, Dana-Farber Cancer Institute
San Francisco, California	Jennifer Clarke/ Susan Chang/Mitchel Berger	Department of Neurological Surgery, University of California, San Francisco

# The EANO palliative care task force: better knowledge for neuro-oncologists, better palliative care for brain tumor patients

Dr Andrea Pace

Neuro-Oncology Unit, Istituto Tumori Regina Elena, Rome, Italy

Dr Martin Taphoorn, Professor of Neuro-Oncology

Leiden University Medical Center and Haaglanden Medical Center, The Netherlands



Above: Some of the members of the EANO palliative care task force. Left to right: Andrea Pace, Emilie Lerhun, Kathy Oliver, Linda Dirven, Helen Bulbeck, Johan Koekkoek, Martin Taphoorn, Roberta Ruda, Christine Marosi, Heidrun Golla, Roeline Pasman, Ingela Oberg, Robin Grant. Others in the EANO palliative care task force not pictured here are: Jane Fleming, Ally Rooney, Roger Henriksson, Stefan Oberndorfer and Michael Weller.



OVER the last years there has been increasing attention towards palliative and supportive care issues in brain tumor patients and several neuro-oncological groups have demonstrated their interest in this field with important and relevant scientific output. However, the themes of palliative and supportive care, particularly

concerning the end-of-life stage of disease, do not seem in all cases to be adequately addressed by the neuro-oncology community in clinical practice.

## The importance of palliative care in neuro-oncology

There is an increasing awareness of the importance of palliative

care not only in the field of oncology but also in neurology and other branches of medicine. Recent evidence for the effectiveness of palliative care for patients with cancer - showing that early palliative care increases length of survival and reduces hospital care for patients with lung cancer - has contributed to shaping the modern concept of palliative care.

Palliative care is defined by the World Health Organization (WHO) as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”. The WHO definition also affirms that palliative care is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life.

However, there is still a lack of knowledge in the neuro-oncology community about the themes of palliative and supportive care, especially concerning the last stage of disease. Particularly, in



neuro-oncologic palliative care we observe an emergent interest but very low quality of data, mostly coming from the experience of single groups.

The palliative care literature has expanded, with the number of papers in palliative care increasing from 0.2% to 0.8% between 1970 and recent years. Literature searches about palliative care in neuro-oncology identify more than 200 articles but no randomised controlled trials have been published in the field. Most of the studies in neuro-oncology palliative care are retrospective, small, clinically heterogeneous, mostly reporting single institution experiences and of poor quality and external validity. In general they fail to provide good evidence to guide clinical practice.

There is a large consensus about the fact that evidence-based medicine principles are very difficult to apply in palliative care. Other approaches, including narrative medicine, consensus conferences and expert opinion have been suggested for a better definition of palliative care issues.

### The EANO Palliative Care Task Force

In this context, the European Association of Neuro-Oncology (EANO) has recently established a task force for palliative care with the aim to define the “state of the art” in palliative and supportive care as well as end-of-life care in neuro-oncology. The goal of this collaborative network was to reach consensus on the optimal palliative care to deliver to people with primary brain tumors on the basis of the available literature evidence and current clinical practice, and to identify gaps in knowledge within the selected relevant issues in this field.

The EANO palliative care task force is an international collaborative network including the European groups most involved in this field, integrating knowledge from an interdisciplinary, multiprofessional team. A wide range of expertise is represented in the initiative including neurologists, a psychiatrist, a radiotherapist, oncologists, palliative care specialists, a nurse, and brain tumor patient associations.

At the beginning of the project, in consensus meetings during November 2015 and April 2016, three main areas of neuro-oncological palliative care were identified as relevant for the work of the EANO task force: symptom management; patient and caregiver needs; care in the end-of-life (EOL) phase.

Several areas have been highlighted for particular consideration such as treatment of relevant symptoms like pain/headache, epilepsy, venous thromboembolism, fatigue, mood and behavioural disorders, neurological deficits for which rehabilitation is required, and cognition. Patient and caregiver needs include supportive and psychosocial needs issues and education for all professionals involved in the care of these patients and their families. Moreover, the task force also focused their discussions on end-of-life issues including delirium, nutrition, hydration, respiration, advance care planning and the organisation of the EOL phase.

The quality of evidence has been classified according to the European Federation of Neurological Societies Guidelines. After extensive discussions about the quality of evidence found within the literature search, a consensus was reached by the team about the importance of reporting the strength of recommendations and integrating this information into each topic discussed. In the case

of limited literature evidence, the EANO palliative care task force provided their expert opinion in order to give more guidance to clinicians involved in the care of glioma patients.

### A milestone – the emergence of guidelines for neuro-oncologic palliative care

The EANO palliative care task force work has led to a first important scientific outcome with the production of guidelines. The results of the literature search are integrated with expert opinion and recommendations on the treatment of the most relevant issues in brain tumor palliative care. The palliative care guidelines are in press in *The Lancet Oncology*.

Despite the challenges inherent in neuro-oncological palliative care research, the EANO task force initiative represents an example of a collaborative research network and may help to develop an active palliative care culture within the neuro-oncological community with the aim to further enhance the quality of palliative care for glioma patients and their families. ■



Above: Donating their steps to the Walk Around the World for Brain Tumours 2016 the Ferguson family (Hillary L, Chavis Ferguson II, and Chavis) round the final curve of the 1K.

## Southeastern Brain Tumor Foundation's 17th Annual Race for Research

NEARLY 1,100 people from the local brain tumor community surrounding Atlanta, Georgia (US) gathered in support and for the purpose of generating funds for brain tumor research. Sixty-six teams were formed and members were running or walking in honor, or in memory, of a loved one stricken by the diagnosis of a brain tumor. One hundred and thirty-nine of the event's walkers symbolically donated 559 kilometres to the Walk Around the World for Brain Tumours efforts.

The Dick Comanzo Memorial Award, the Karen Herman Memorial Award, and the Phil Jory Scientific Award totalling USD \$150,000 were proudly presented during the Race For Research to the three most recent research grant recipients.

Since 2005, the SBTF has awarded 41 research grants totaling more than \$2.3M. ■

# Communication is key in brain tumor management

Randall Porter M.D, neurosurgeon at Barrow Brain and Spine  
Phoenix, Arizona, United States



Above: Dr Randall Porter, neurosurgeon

Communication between doctors and brain tumor patients is essential for the effective delivery of health care. However, there is often a mismatch between clinicians' level of communication and patients' level of comprehension. Patients don't recall or understand for a number of reasons including normal memory decline, poor health literacy, the use of complex medical terminology, information overload, emotionally charged discussions, organic disease, medications that impact cognition, and treatments that impact the mind.

In fact, research shows there is a large chasm between doctor and patient when it comes to communication. In one study, in the journal of *Experimental Aging Research*, patients were read an eight-minute video on osteoarthritis, and it was administered in two formats. In this study, younger patients performed better than older only in the immediate recall period, but not at one week and one month. Astonishingly, recall was below 25% for both groups in the immediate period, and less than 15% at one month. In one study (*British Medical Journal*, March 1988), 27% of patients did not even know what organ was operated on after surgery.

Further, studies show that providers have poor insight into their unsatisfactory communication skills, and the patients' lack of understanding. Communication styles vary among health care providers, health literacy impacts understanding, and patients frequently are intimidated by the "white coat syndrome" or don't even know what to ask. As such, patients and doctors must strive to improve understanding, communication, and recall. These goals are not easily accomplished in an increasingly complex environment, with pressured appointment times.

## Communication between doctors and brain tumor patients

Patients with brain tumors, in particular, face unique challenges when communicating with their health care providers. The diagnosis itself creates a stressful environment that can impact concentration, understanding, and recall. Furthermore, treatments such as surgery, radiation, chemotherapy, seizure medication, and pain medication can inhibit memory, understanding and concentration.

Proper informed consent is a necessary part of the process in order to achieve shared decision-making (patient and provider). However, studies show that patients forget up to 80% (McGuire, *Experimental Aging Research*, 1996) of what the doctor tells them. Proper informed consent is achieved less than 10% of the time (Braddock et al, *JAMA*, 1999). Patients also tend to remember the benefits more than the risks of surgery. As such, techniques to improve recall, understanding and the ability to share must be implemented.

Patients have employed many different techniques to improve recall. They bring friends or family members to doctors' visits, take notes, bring questions, use recorders, video cameras, and smart phones to record their doctors. However, patient-recording devices have multiple problems. They are not secure, can be used out of context, can inadvertently commit a HIPAA (Health Insurance and Portability and Accountability Act) violation in the US, and a copy of the recording is not shared with the provider.

## Good health literacy is crucial

Health literacy, (according to the US National Center for Education Statistics and the National Assessment of Adult Literacy), is defined as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions." It is estimated that 78 million Americans have low health literacy and

this has a significant impact on doctor-patient communication. It is also known that patients with poor health literacy cost the health care system almost three times more than those with adequate literacy (Weiss BD, Palmer R, *J Am Board Family Pract*. 2004;17:44-47).

The implications of poor doctor communication are many and can include: noncompliance, dissatisfaction, unnecessary readmissions, poor health outcomes, litigation, and costly medical care. Non-compliance with medical care has been estimated to cost the American health care system US \$289 billion (*Annals of Internal Medicine*, December 2012). Consumer Reports National Research Center in America completed a survey of one thousand patients. The biggest complaint was a perceived unclear explanation of the diagnosis.

### The importance of good communication – a personal example

I experienced first-hand the challenges of patient-health care provider communication from the concerned family's perspective in 2003. I was practicing in Arizona and my father was in Illinois facing a diagnosis of prostate cancer. Both of my parents were well educated and my mother actually worked in the medical field most of her adult life. I was surprised at how difficult it was for both of them to effectively verbalize what the doctor had said during the appointment.

Fortunately for me, my father's doctor was willing to get on the

phone and answer all the questions I had. As health care providers, we know it is unrealistic to think we have the time in each case to spend on the phone with family members after a primary visit with our patient. My experience made me start to question how I communicated with my patients and forced me to find ways to improve my own patients' ability to remember, better understand and recall all the information I was giving them. So, in 2008, I started recording my interactions with my patients and sent them home with a CD of their appointment when they left my office. The response was so positive that I continued to refine the process.


### A common sense approach

I think some of the best advice regarding communicating is to remember to use common sense. I try and remember when talking to patients and/or their families that this is someone's mother, father, brother, sister, son or daughter, and it could just as easily be my mother, father, brother, sister, son or daughter. I try to approach each consultation and all recommendations in that manner.

### So why should we as health care providers strive to improve communication?

Because patients who understand their providers are more likely to acknowledge their own health problems, understand their treatment options, modify their behaviour accordingly, follow their medication schedules, and achieve better outcomes. We all have a stake in this. ■

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# New Understanding of Diffuse Intrinsic Pontine Glioma (DIPG) Provides Real Hope

Dr Mark W. Kieran, Director

Pediatric Medical Neuro-Oncology, Dana-Farber Cancer Institute, Boston, United States

FOR 50 years, diffuse intrinsic pontine glioma (DIPG) outcomes have stood still while clinical advances in virtually every other pediatric tumor have marched forward. We accepted the diagnosis of these highly malignant, incurable tumors based on clinical and radiologic features alone. After all, there was ample clinical and published data to show that biopsy did nothing to change the treatment or prognosis but was associated with the risk of significant neurologic damage.

In 2002, we recognized that this long-accepted dogma from the past 30 years was hindering significant advances in this disease and condemning another generation of patients to the same horrific outcome. With the increased proficiency in small, minimally invasive guided biopsies came advances in neurosurgical techniques for this disease; while the remarkable, almost sci-fi-like advancements in nano-scale molecular biology allowed for whole genome sequencing to be performed on even smaller pieces of tissue.

Despite the insurmountable regulatory hurdles in the United States at that time preventing a protocol from going forward, a medical team under the direction of Dr. Puget in Paris, France, forged ahead in 2007, conducting more than 20 successful biopsies. This provided the necessary impetus for the regulatory authorities in the U.S. to finally agree that safe biopsy of the pons was feasible and ultimately launched the first national, multi-institutional clinical trial of up-front biopsy guided therapy for DIPG. Through this trial, we aimed to explore whether patients with DIPG could benefit from precision medicine, a form of care through which investigators strive to select targeted treatments based on each patient's tumor biology. The team collected and sequenced DIPG samples to learn more about which alterations were causing disease and uncovered key details about previously mysterious driver mutations. This new knowledge has the potential to transform treatment for these patients by informing therapy decisions and allowing for the selection of more targeted agents.

Building on the success of this initial study and the work of our colleagues in Paris, we are developing a new national clinical trial to further understand how best to deliver precision medicine to these patients. Through this trial, patients with DIPG will undergo tumor biopsy at the time of diagnosis. Tumor tissue will be subject to detailed genetic sequencing to pinpoint the alterations driving each specific tumor. Based on these analyses, we will then select the appropriate therapies for each patient based on their genomics and test the efficacy of these



Above: Dr Mark W. Kieran

targeted drugs in addition to standard radiation treatment. As new therapies are discovered and developed, they will also be incorporated into the trial.

With the increasing complexity of science and medicine, teams were constructed that would allow us to understand aspects of DIPG that until now had gone unnoticed or been poorly studied. Those aspects include:

**Heterogeneity between DIPG.** Early molecular analyses have identified three subtypes of DIPG. Whether these represent three different diseases or three variations of one disease is still under investigation. The recognition that the mutational profiles of DIPG can differ has significant implications for the development of effective therapies and how we incorporate them into therapy.

**Heterogeneity within DIPG.** While cancer is recognized as a clonal disease (tumors arise from a single cell), it rapidly diversifies through random mutation. To treat DIPG effectively, we will therefore need to understand the type and extent of variations within the tumor. To achieve this, we have begun

an exciting program of single cell sequencing (both RNA and DNA) to help identify which mutations arose first and how the accumulation of mutations accounts for the resistance of these tumors to therapies trialed to date.

**Precision medicine for DIPG.** From the initial sequencing efforts arose the recognition that DIPGs are different from other high-grade gliomas in children and very different from malignant gliomas in adults. We now realize that applying adult treatments to pediatric patients with DIPG has little chance of working, and unfortunately, we have 50 years of proof that this is the case. To overcome these issues, drugs and combination therapy targeting DIPG will need to be developed for the mutations observed in this disease, some of which (ACVR1 for example) are not known to occur in any other cancer (pediatric or adult). Cell and animal models (developed through the tissue cores) are now being tested to identify the best, most active agents and combinations.

**Understanding the microenvironment.** Tumor cells do not grow in isolation. They require a microenvironment that supports their nutritional, metabolic and structural needs. Understanding the complex interaction of the microenvironment is therefore critical for optimal therapy. Using a new methodology developed by Dr. Rosalind Segal, MD, PhD at Dana-Farber Cancer Institute in combination with single cell sequencing to analyze the components of tumor microenvironment (e.g. adjacent normal cells, endothelium and pericytes of the tumor blood vessels, immune cells, etc), a true picture of the whole tumor can be achieved. These models also provide the ideal method for developing and screening novel agents.

**Penetrating the blood-brain barrier (BBB).** The most effective drug in the world is of no value if it cannot get to the cells it needs to kill. Hundreds of clinical trials have tested drugs that do not penetrate the BBB, and the negative results observed are therefore not a complete surprise. Using a new technique developed by Dr. Nathalie Agar, PhD at Dana-Farber Cancer Institute, she can now determine the amount of drug that will penetrate into each different part of the brain and spine (since penetration through the BBB is not uniform), how long it remains and whether the concentrations are sufficient to achieve the desired effect. This means that only agents that can penetrate into the pons are moved into clinical trials, reducing the number of patients getting potentially ineffective therapies and increasing the chance of identifying an active agent or combination of agents. Equally exciting are developments in direct administration of drugs into the CNS via convection-enhanced delivery (CED) for those agents that cannot be modified to penetrate on their own.

**Harnessing the immune system.** DIPG is the worst of the worst in regard to survival outcomes for these children, and we need all of the help that we can get. Understanding how DIPG evades the immune system and how to reverse this is a major opportunity to improve the treatment of this disease. With the recent discovery of a number of immune modulating therapies (checkpoint inhibitors, vaccine trials, cellular therapies), we now have an opportunity to use these approaches alone and in combination with radiation and the treatments discussed above.

DIPG is still an incurable disease, but for the first time, light shines at the end of the tunnel. We have made more progress in

our understanding of this disease in the last five years than in the prior 50 years.

Using the knowledge gained from these studies and those going on in programs around the world, we finally have the pieces in place to develop novel clinical trials that will rapidly and efficiently identify active agents while eliminating those that are not. Our new adaptive clinical trial for DIPG recognizes that DIPG is not a single uniform disease and will treat patients accordingly by incorporating the tumor's individual mutations and heterogeneity. It will incorporate combinations of therapy rather than single agents, and it will combine modalities (radiation, biologic, targeted and immune therapy).

With all of these new advancements in place, there is finally reason to have real hope! ■

## Walking in Worcestershire



ROSEMARY Wormington (Head of Support at UK-based Brain Tumour Support) said that a group of enthusiastic walkers gathered at Gheluvert Park in Worcester, England at 11am on Sunday 16 October 2016 in order to collect miles for the International Brain Tumour Alliance's Walk Around the World for Brain Tumours. Rosemary said: "Despite the rain, it was a great day. Pat Mayo, the walk organizer, had picked the venue which offered a very easy one-mile route that started and finished at a café. People could do as many or as few miles as they wished. We managed to clock up 25 miles between us and about 20 coffees and cake! People often talk when they walk and we all shared our thoughts and experiences of brain tumour issues. Everyone came away feeling uplifted. A great day!" ■



Above: The Worcestershire Brain Tumour Support Group once again supported the IBTA's Walk Around the World for Brain Tumours, by walking around one of the many beautiful parks in Worcester, England

# What's wrong with Shona?

Professor Willie Hamilton, Professor of Primary Care Diagnostics  
University of Exeter Medical School, United Kingdom

Potential brain tumours are challenging to diagnose because they can mimic symptoms caused by other diseases. Here, Professor of Primary Care Diagnostics Dr Willie Hamilton takes us through the thought processes that a general practitioner might have in evaluating a possible brain tumour diagnosis.

SHONA doesn't come to the health centre that often.

When she does it's usually with one of her daughters, rather than for herself. She works in the accounts department of the local electricity firm. Her previous good health makes her seeing you with a persistent headache that bit more surprising. Already your 'sniffometer' – that sixth sense that says 'this is unusual' – is beginning to twitch.

The headache has been pretty well constant for four weeks, is only a bit eased by paracetamol, and is interfering a bit with Shona's life. She's not missed work, in part because she and her boss have an iffy relationship, and she's worried he'd take some sick leave amiss. Anyhow, she's always been one for coping with minor problems.

At this point, a general practitioner (GP) will want to know what the patient wants. This sounds obvious to patients, but is far less obvious to doctors. Does she want a diagnosis? Does she want treatment? Is she worried she has a brain tumour? Does she want a sick note? Is she concerned with all four of these questions?

Many patients who are fearful of cancer feel it's silly to say so, lest the GP label them neurotic. Yet it's one of patients' commonest fears. In practice, until the GP and the patient have a common 'agenda' then the patient won't feel properly listened to. In Shona's case, most GPs would gently ask what her concerns are, and what her expectations are.

Once the GP has this fuller picture, they'll generally measure the patient's



Above: Professor Willie Hamilton

blood pressure, and look at the back of the patient's eyes. This is the bright instrument shining into the eyes and it can reveal swelling of the optic disc, which can be related to raised fluid pressure within the brain. It's actually jolly hard to be certain about this swelling, as we GPs don't see it very often. In truth, examination of a patient like Shona is nearly always normal.

Now comes the tricky bit.

We probably don't have a diagnosis (I'm being honest here, despite my job title of Professor of Primary Care Diagnostics!), and we probably won't get one. It may be tension headache (this tricky boss, this worry that it may be a brain tumour....). It may be migraine – though that's usually quite easy to diagnose. It may be (but almost certainly isn't) a brain tumour. Based on a study I did years ago, but which hasn't yet been repeated (1), the

actual risk of a brain tumour here is about 1:1000.

But...somebody has to be that one in that 1000. Is it Shona?

There are positive features here: she's not had any weakness, confusion, or worse, had a seizure. Each of these would increase the chance of a brain tumour diagnosis quite a bit. So, should the GP refer Shona to a neurologist for a brain scan?

There is no right answer here, and it depends on many things, Shona, first of all. If she is so worried this may be a brain tumour, it may simply be that the only way to alleviate that worry is to have a negative brain scan. There is some evidence this works.(2) Patients like Shona, whose brain scan is negative, consult their GP less afterwards. This suggests they are reassured (I'm ignoring the possibility that they are so annoyed with their GP that's why they don't consult again).

The next factor is the scan. Awkwardly, negative scans often aren't wholly negative. They sometimes identify small abnormal blood vessels, or other things which weren't causing the headache in the first place. Our neat word for these is 'incidentalomas'. They are a bother, as you generally need repeat scanning periodically to check they are not growing. Next, we need to consider the costs, and the UK National Health Service. Scans aren't cheap, and every penny spent on a scan is a penny unavailable to be spent elsewhere. It's awkward talking about money and health – but we can't ignore it.



Gosh.... I was asked to write a piece about the GP's perspective on brain tumours, and all I've done is produce questions. Perhaps the old adage is right: the more you know, the more you realise you don't know.

Shona, got better, by the way, without a diagnosis. ■

#### Notes:

1. Hamilton, W. and D. Kernick, Clinical features of primary brain tumours: a case-control study using electronic primary care records. *Br J Gen Pract*, 2007. 57: p. 695-699.
2. Howard, L, et al., Are investigations anxiolytic or anxiogenic? A randomised controlled trial of neuroimaging to provide reassurance in chronic daily headache, 10.1136/jnnp.2004.057851. *J Neurol Neurosurg Psychiatry*, 2005. 76(11): p. 1558-1564.

## From the IBTA Album...



**Above:** IBTA Chair Kathy Oliver (right) with IBTA Senior Advisor Anita Granero (left) from Oscar's Angels in France. In 2016, Kathy and Anita attended the European School of Oncology's (ESO) Masterclass in Cancer Patient Advocacy.



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# Walk Me Home

## Thoughts on being a brain tumour caregiver

Becky Livingston

Canada

ONE thing we know about life is that we don't know anything at all. Life has a way of calling on us to step up when we least expect, or want it. Twice now, I have cared for a dying loved one: my fiancé, Bob, in 2006, and then my 23-year-old daughter, Rachel, in 2010. Both had brain tumours.

"When something is dying it is the greatest teacher," said Zen monk, Shunryu Suzuki.

Indeed, I never knew there'd be so many phone calls to make, appointments to keep, or people to update. I never realized the emotional demands of this journey and the need to bend with changing moods, all the while having to imagine the unimaginable.

But I also never knew that grief, paradoxically, is filled with joy. I never knew it would be a time of such deep, unconditional love, or that in accompanying someone to the end I would be blown open with such gratitude for having shared the journey. It was a transformative experience.

### The Importance of Self-Care in Caregiving

The way we help our loved ones on their brain tumour journey requires that we, too, help ourselves in some small way. Caregiving is depleting. We need to recharge our batteries. Here's what worked for me:

#### 'Be with' as much as 'Do for'

When the demands of appointments, prescriptions, communications and running a household are all-consuming, it's easy to get caught up in the doing. More than anything, your loved one wants you to just be with them. So be with them, however and whenever they need you. Let them take the lead. Listen without judgment. Be okay with silence, and snuggle a lot.



Above: Becky Livingston cared for her fiancé and her daughter, both of whom had a brain tumour

#### Receive, Receive, Receive

On numerous occasions when I wanted to 'do it all', Bob urged me to accept help from others. "They need to help, Beck. They don't know what else to do. Besides, to be constantly strong is a weakness." When

I was able to accept help from others, I became the recipient of more generosity than I would ever have imagined.

#### Find Ways to Replenish Yourself

Know what sustains you. Denying your own needs can manifest into more fatigue, even anger. When Bob was sick, I stopped my weekly yoga classes and quit walking in the woods, activities that had previously helped me find calm and solace in a busy life.

Instead I began to write. Journaling became a lifesaver. I kept track of daily events and documented his deteriorating health, all the time pouring out my sadness, anger and frustrations. I also took up gardening. (We had just moved into our new home, which had a large backyard.) I dug and planted and sweated away in the dirt for months. Gardening gave me hope, the promise of new life in a future without Bob.

Below: Becky and her daughter Rachel, on Rachel's 21st birthday in 2007





Above: Becky and her fiancé Bob, celebrating Christmas in 2004

When my daughter was sick I remembered the words of the social worker at Cottage Hospice where Bob had spent his final weeks: "It's really difficult to take care of someone else if you don't take care of yourself." This time I knew better. I continued my yoga practice, and a good friend regularly

stole me away for walks in Capilano Canyon, a place to breathe, to move my body away from the demands of caregiving.

### Give Them Their Power

Bob was a dying man who was very much alive. By choosing to spare him from all the details of his condition, the day-to-day tasks of running a house and of closing down his business, he felt more alone than ever. "Beck, I'm not pushing up daisies yet," he'd remind me, "I want you to tell me everything, even if I don't understand it all." Dying people need to participate as much as possible in making choices that will affect them now, and after they're gone.

### Assert Yourself

Tell others what you need, and what you don't, even if it feels out of character. Friends at work who organized and dropped off meals to our house knew to bring enough for two servings only, in containers that didn't need returning, to leave them at the front door, and not to ring the doorbell. What initially seemed

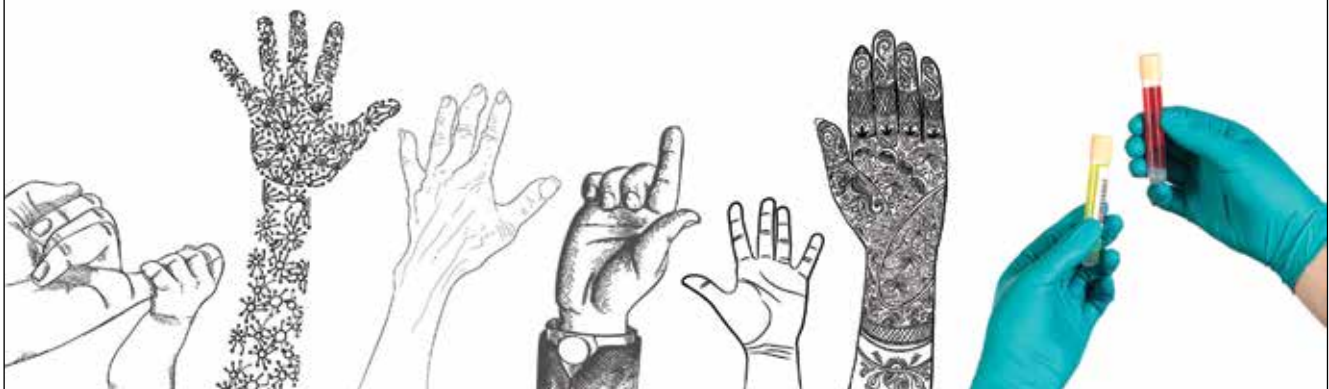
rather harsh, was essential for my peace of mind.

### Go With the Flow

We can't change the reality of a diagnosis, but we DO have control over how we respond to that reality. Bob rarely got caught up in the 'what-ifs', certain that his copious readings of Krishnamurti helped him live life and approach death with courage and dignity.

Caring for a dying loved one gives us the opportunity to see something in ourselves that we'd like to change. Bob inspired me to take it one day at a time; Rachel reminded me to follow my heart. Thanks to them both, I embrace life as it is, grateful for the blessings of each day. After all, as Ram Dass so beautifully said, "We're all just walking each other home." ■

This article has been reprinted with kind permission from the Canadian BC Cancer Agency's *Headlines* newsletter, Spring 2013.



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# The International Low Grade Glioma Registry Enrolls its First 100 Participants

GLIOMA is the most common primary malignant brain tumor in the United States.

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

Despite this, a number of advances are leading to a reclassification of adult glioma using three tumor markers (IDH1, TERT/ATRX, and 1p/19q co-deletion) in place of the traditionally used World Health Organization (WHO) histo-pathology groupings (astrocytoma, oligoastrocytoma (mixed), and oligodendroglioma). Using these three markers, new subtypes have been identified leading to improved stratification of disease risk and prognosis. This discovery - as well as the finding that each subtype has unique clinical features, specific additional acquired tumor alterations, and is associated with specific inherited genetic variants - has led to a paradigm shift within the field of clinical neuro-oncology. However, the majority of patients studied have had high grade (III/IV) tumors. Thus larger numbers of well-annotated LGG cases with clinical as well as tumor and constitutive materials are needed for separate analyses of LGG patients.

To begin such an investigation, Elizabeth B. Claus, M.D., Ph.D., Professor and Director of Medical Research at the Yale School of Public Health and Attending Neurosurgeon at Brigham and Women's Hospital (United States), is now enrolling patients into the International Low Grade Glioma (LGG) Registry. The LGG registry, a global effort to study LGG, is using web- and smartphone-based recruitment



Above: Elizabeth B. Claus, M.D., Ph.D., Professor and Director of Medical Research at the Yale School of Public Health and Attending Neurosurgeon at Brigham and Women's Hospital

methods with the goal of enrolling approximately 2000 registrants over the next several years.

"The overarching theme of the registry is to create a large, collaborative database for researchers to learn more about the best treatment choices for LGG as well as to gain information on how to maximize quality of life and neuro-cognitive function. Data will also be collected on activities of daily living including the ability to work,

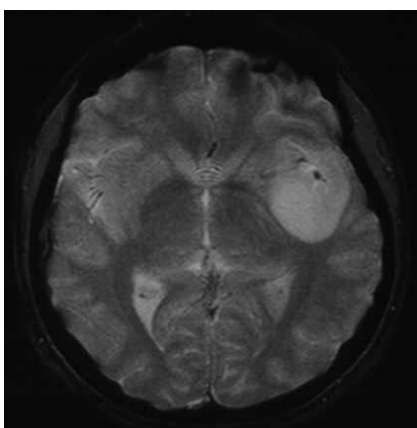
drive, sleep, exercise, or take care of oneself and family," says Dr. Claus

The study has received pilot funding from the American Brain Tumor Association (ABTA - [http://www.abta.org/about-us/news/press-releases/PFC2016\\_EnrollmentLGGRegistry.html?referrer=https://www.google.com/](http://www.abta.org/about-us/news/press-releases/PFC2016_EnrollmentLGGRegistry.html?referrer=https://www.google.com/)), the National Brain Tumor Society (NBTS - <http://blog.braintumor.org/press-releases/national-brain-tumor-society-awards-1-million-in-new-research-grants-for-projects-studying-low-grade-gliomas/>), and the LOGLIO collective (a low-grade glioma research collective based at the University of California, San Francisco).

Enrollment into the registry is via the Internet and thus is open to patients throughout the world. Participants are asked to submit a pathology report to confirm eligibility and are then asked to complete a short online questionnaire as well as provide a saliva sample (sent via the mail). An introductory video on the study is available at <https://www.youtube.com/watch?v=cbF5LpIY5dA>.

Below: Scan this QR code with your smartphone to visit the website for the International Low Grade Glioma Registry

Below left: MRI image of a low grade glioma



Registration opened at the ABTA's "Partners in Treatment and Care" meeting in Chicago in July 2016. In just the first six months, over 100 LGG patients joined the registry. To date, participants include residents from 21 states within the United States and four countries, including Canada, Spain, France, and the United Kingdom.

Dr. Claus notes "It has been wonderful to connect with so many LGG patients from around the country as well as the world. As this is a group of relatively young patients, they are quite comfortable with using the Internet to gain and share information regarding their diagnosis, and they feel strongly about advocating for themselves and for greater awareness of their diagnosis."

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

To join the registry or learn more, email [glioma@yale.edu](mailto:glioma@yale.edu), visit [www.abta.org/LGGregistry](http://www.abta.org/LGGregistry) or scan the barcode at left.

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.

## Commonly Asked Questions:

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

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

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

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

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

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

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

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

## *From the IBTA Album...*



Left: IBTA Chair Kathy Oliver is part of the EORTC's SISAQOL initiative – "Setting International Standards in Analysing Patient-Reported Outcomes and Quality of Life Endpoints Data". Kathy is pictured at the European Cancer Congress in Amsterdam (January 2017) in front of the poster which the SISAQOL group presented.

# Brain Tumor Survivor Ran 7 Marathons on 7 Continents in 7 Days to Raise Awareness and Funds for Research

## BethAnn Telford completes the 2017 World Marathon Challenge

Nicola Beddow, ABC<sup>2</sup> (Accelerate Brain Cancer Cure)

United States



Above: Flying the US flag in Miami – BethAnn Telford, a malignant meningioma patient, celebrates her amazing achievement of successfully completing the 2017 World Marathon Challenge

BETHANN Telford, an endurance athlete with a brain tumor (malignant meningioma), successfully completed the 2017 World Marathon Challenge on seven continents in seven consecutive days. It's a mind-boggling accomplishment for any athlete, but Telford went above and beyond. She ran to raise global awareness about brain cancer and raise \$1 million for research supported by ABC<sup>2</sup> (Accelerate Brain Cancer Cure).

The 33 competitors from 13 different countries ran in Union Glacier, Antarctica; Punta Arenas, Chile; Miami, USA; Madrid, Spain; Marrakech, Morocco; Dubai, UAE and Sydney, Australia. Participants spent about 60 hours in the air flying 38,000 km from the start point

in Antarctica to the finish in Australia. Finishers ran 295 km or 183 miles in total.

At 47 years of age, Telford trained for the World Marathon Challenge for more than a year. She typically worked out more than three hours a day by doing a variety of running, strength and core exercise routines.

"BethAnn's completion of the World Marathon Challenge is a remarkable and heroic story," said Max Wallace, CEO of ABC<sup>2</sup>. "She is our longtime friend and a champion for the brain tumor community."

Telford was diagnosed with a brain tumor in 2005. She has not driven a car in 12 years because she has seizures often and





Above: BethAnn Telford crosses the finishing line in Antarctica

is blind in her left eye. Her brain tumor also affected her bladder, which led to surgery for a bladder augmentation.

"I've overcome so many obstacles because of this cancer," said Telford. "As I ran around the world, I found a way to push through the pain and the fatigue by remembering the people I'm representing. I wish to be an example of hope and inspiration to so many others fighting cancer or anyone who has faced a setback in their life."

"The hardest day of the seven marathons was probably Dubai as it was extremely hot and I had to really listen to my body and slow down," said Telford. "My best day was in the USA when we ran Miami. I got to see my parents, Robert and Susanne Telford, as well as many friends who came to support me and run along with me."

Telford, who started running marathons 15 years ago, ran to raise funds for brain cancer awareness and research. It was especially important for her to honor the children diagnosed with the disease.

"Since I wasn't able to have kids, I've 'adopted' hundreds and hundreds of children [with pediatric cancer] where I've tried to instill in them, and their families, that there's hope," she said. During the marathons, Telford ran with pictures of those children clipped to her race belt. She also wore running shoes decorated by the children.

On the last leg of the World Marathon Challenge in Sydney, Australia, Telford was greeted at the finish line by Gerry Tye, a pediatric cancer advocate. Tye's young son passed away from brain cancer. "Similar to the U.S., Gerry told me that in Australia, brain cancer is not well publicized and the funds for research are lacking," said Telford.

Since 2005, Telford has raised more than \$835,000 for brain tumor research. Her goal is to cross the million-dollar mark with donations supporting her World Marathon Challenge. The donations support ABC<sup>2</sup>, a Washington DC-based venture



Above: BethAnn in Marrakech wearing shoes decorated by a child with a brain tumor

philanthropy nonprofit organization that drives cutting-edge research and treatments for brain cancer.

"This epic adventure has truly made me realize that there are so many more people around the world who need advocates such as myself," said Telford. "I have met, or heard from, so many beautiful individuals over this journey who have a vested interest in finding a cure." More than 70 media outlets worldwide have covered Telford's story, including those in Australia, Brazil, Canada, Chile, Germany, Hungary, Indonesia, Spain and the United States.

"My finish line is when we find out that we did find a cure for cancer. When that does happen, that's my finish line, not these epic events," Telford said. "I think people are going to be more amazed when the media outlets report that there is a cure for these cancers." ■

# All.Can - striving for greater efficiency in cancer care

Suzanne Wait, Health Policy Partnership  
London, United Kingdom on behalf of the All.Can initiative



In 2011, the Lancet Oncology commission for sustainable cancer care warned that cancer was at a crossroads – and that, if we failed to make the right decisions, we may be compromising our ability to provide high-quality care to cancer patients in years to come.(1) This crossroads prevails today: on the one hand, the field of cancer has seen tremendous advances in recent years that promise to transform outcomes for patients with many types of cancer – not just in terms of drugs, but also in surgery, radiotherapy, imaging, models of care and our growing ability to personalise treatment.

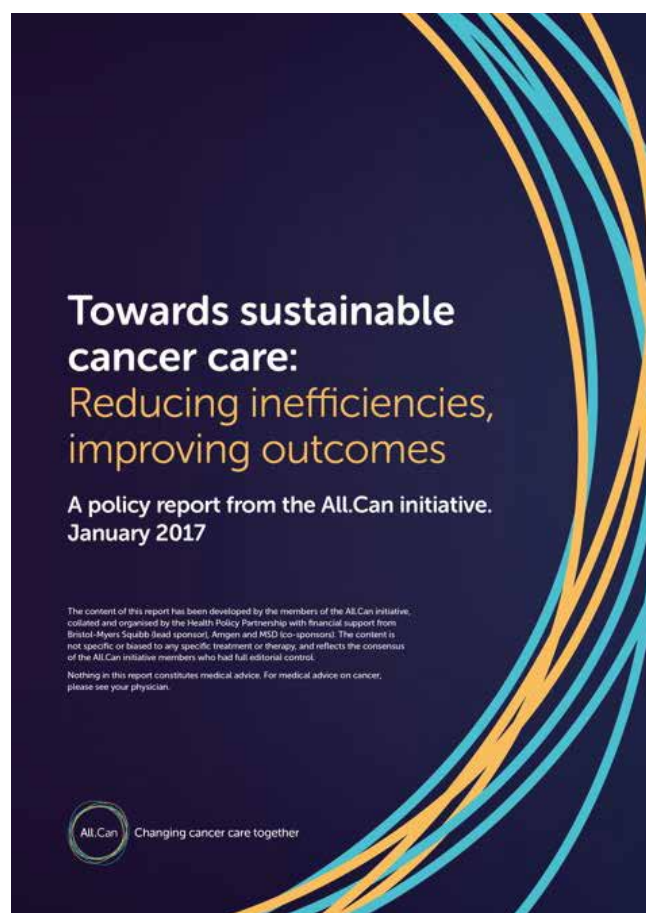
On the other hand, the prevalence of cancer is increasing, and with it the demands and complexity of cancer care. Financial pressures on health care systems mean that reimbursement for many new treatments for cancer is often either delayed or denied, and out-of-pocket costs to patients are rising in many countries as a result.(2) There is also a growing concern internationally about the ‘financial toxicity’(3) caused by cancers like brain tumours for many families.

This situation is both worrying and unsustainable if we want to continue to offer cancer patients the best outcomes possible and abide by the principle of social solidarity that lies at the heart of most publicly-funded health care systems.

## Opportunities for change

The good news is that there is clear evidence that solutions are both possible and achievable: a recent publication by the Organisation for Economic Cooperation and Development (OECD) found that up to 20% of health care budget was spent on ineffective or ‘wasteful’ practices.(4) A study in Germany found that over €72 billion could be saved every year through better coordination of care leading to reduced hospital admissions.(5)

What these figures point to is not just that there is considerable waste across our health care systems, but that there are real opportunities for change. For example, a World Health Organisation (WHO) report estimated that removing wasteful



Above: The All.Can policy report, launched in January 2017 at the European Cancer Congress in Amsterdam, The Netherlands

interventions could deliver an efficiency saving of between 20-40%.(6) Similarly, the potential gain from reducing inefficiencies across European health care systems is thought to be two years of additional life expectancy.(7)

These figures are compelling – and are a clear indication that we can do better with the resources we have.

This was the underlying rationale for the creation of a new initiative, All.Can ([www.all-can.org](http://www.all-can.org)), which aims to create political engagement on the need to improve the efficiency of cancer care. The term ‘efficiency’ should not be misconstrued as being equivalent to short-term cost cutting efforts – or the mere



identification of waste. Instead, driving efficiency across cancer care requires a long-term vision that starts by asking what matters most to patients, looking at where resources are not being used effectively to achieve these (waste), and identifying sustainable ways to re-focus resources on attaining these outcomes.

### All.Can releases its new report on reducing inefficiencies and improving outcomes

All.Can recently published a report which offers several powerful examples of where greater efficiencies may be achieved across all aspects of cancer care.

One such example is the PROCHE programme at the Georges Pompidou Hospital in Paris, France. By hiring a nurse to telephone patients a few days before each chemotherapy session and check on any side effects from the previous round of chemotherapy in advance of the next appointment, this programme managed to reduce time spent by nurses and patients at each chemotherapy session, decrease drug wastage and increase the overall productivity of the chemotherapy unit.(8)



Another example is that of GE Healthcare, which painted exciting adventure themes – a pirate ship, a space shuttle - on MRI machines and then created stories around them to help reduce the anxiety felt by children undergoing MRIs. By doing so, imaging units managed to reduce the number of cancelled MRI sessions as well as the use of sedation in children, not to mention lowering the anxiety levels of children and their parents. In fact, patient satisfaction increased by 90%.(9)

The above examples are compelling in their simplicity, and remind us of three important facts:

- First, any efforts to improve efficiency must start with a clear understanding of what matters most to patients, and then strive to find ways to achieve this.
- Secondly, innovation and efficiency are two sides of the same coin – and innovation does not need to be expensive.

- Thirdly, efforts to improve efficiency should not be seen as one-offs, but be built into health care systems with appropriate mechanisms to measure and evaluate practices, remove those that do not produce meaningful patient outcomes, and prioritise those that do - thereby creating a continuous cycle of improvement over time.

### Challenging and important questions

Many of the messages contained in the All.Can report resonate strongly for the brain tumour community – where patients are often caught in this crossroads between the promise of new treatments and affordability challenges. As Kathy Oliver, Co-Director of the IBTA, states in the report, “As a patient, it is extremely frustrating and desperately worrying to be told that there is not enough money to fund the innovative cancer treatments you need when there is so much obvious waste within the health care system.”



The All.Can report does not try to address all of the issues relating to access to innovation, affordability, efficiency and removal of waste. Its focus is on the need to improve efficiency within existing cancer care as a necessary starting point to protecting the sustainability of cancer care. The report also raises important questions that all involved stakeholders – health care professionals, regulators, politicians, academia, pharmaceutical and device industries, as well as patients and their families – should ask, such as:

- Do we really understand what matters most to patients?
- Are we measuring these outcomes in a systematic way to assess the impact of interventions and practices?
- Do we have mechanisms in place to identify and remove wasteful practices or interventions?
- And finally, what barriers (systemic, cultural, or otherwise) may need to be removed to improve efficiency and truly focus on what matters most to patients across the care spectrum?

These are challenging questions – and addressing them is anything but an academic exercise. The All.Can group hopes to help find the right answers, drawing on its multidisciplinary membership to identify pragmatic solutions and actionable policy recommendations. One of its key activities in 2017 will be to gather perspectives and evidence of waste as well as opportunities for greater efficiency in cancer care from patients, nurses and other health care professionals. This evidence may provide an important starting point to channel efforts where they are most needed and where the greatest gains for patients and their families may be made. ➤





**All.Can Changing cancer care together**

*All.Can comprises leading representatives from patient organisations, policymakers, health care professionals, research and industry. All members contribute their time for free to the initiative, and all publications from the group reflect consensus of the members, who hold full editorial control. The All.Can initiative is made possible with financial support from Bristol-Myers Squibb (lead sponsor), Amgen and MSD (co-sponsors). None of the content of All.Can discussions, publications or activities is specific or biased to any individual/combination treatment or therapy.*

For further information about All.Can, please contact Suzanne Wait (secretariat) at [secretariat@all-can.org](mailto:secretariat@all-can.org). To read the full policy report, see [www.all-can.org](http://www.all-can.org).

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# SPECTAbraIn

**Enabling discovery and therapeutic advance in precision medicine for brain tumors**



The identification of molecular alterations in cancer and their specific and selective targeting has significantly improved treatment in cancer patients. Following the EORTC mission to develop, conduct, coordinate, and stimulate translational and clinical research on cancer, and the successful implementation of SPECTAcOLOR and SPECTALUNG, the EORTC Brain Tumor Group has developed SPECTAbraIn. Oncologists now have access to a clinically annotated biobank and molecular tumor profiling database for brain tumors, allowing relevant translational research and access to clinical trials for smaller cohorts of patients with specific molecular profiles.

#### Contact

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**EORTC** *The future of cancer therapy*  
European Organisation for Research and Treatment of Cancer  
[www.eortc.org](http://www.eortc.org)

The International Brain Tumour Alliance has contacts in the following 111 countries. It also distributes its annual magazine, *Brain Tumour* in these countries:

Afghanistan ■ Albania ■ Algeria ■ Argentina ■ Australia ■ Austria ■ Bahrain ■ Bangladesh ■ Belarus ■ Belgium ■ 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 ■ 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 ■ Zimbabwe



European  
Reference  
Networks

## ERN EURACAN

Rare Adult Solid Cancers

**European Reference Networks (ERNs)** are virtual networks involving healthcare providers across Europe. They aim to tackle complex or rare diseases and conditions that require highly specialized treatment and a concentration of knowledge and resources.

The **ERN EURACAN** is a multi-domain ERN, covering all rare adult solid cancers and grouping them into 10 domains. The management of rare cancers poses significant diagnostic challenges, sometimes with major consequences for patient quality of life and outcome. Inappropriate management of these patients may also result in an increased risk of relapse, and risk of death.

**EURACAN** aims to establish a **PATIENT-CENTRIC** and sustainable network of multidisciplinary research-intensive clinical centres focused on rare adult cancers in close collaboration with **PATIENT ADVOCACY GROUPS** with the underlying vision to **HARMONISE** and drastically improve the **QUALITY OF CARE** of all rare European adult cancer patients; improve the **UNDERSTANDING OF PATIENTS** and physicians and ensure an optimised **ACCESS TO CLINICAL INNOVATION** in this field across all Member States of the European Union.



**Contact :** EURACAN Coordination team - Centre Léon Bérard - Muriel Rogasik : [muriel.rogasik@lyon.unicancer.fr](mailto:muriel.rogasik@lyon.unicancer.fr)

# A Poignant Remembrance Day 2016

Sharing experiences and remembering our children together

## Catherine Klopper, Rainbows and Smiles South Africa

WHEN a child is diagnosed with cancer, parents are thrust into the harried new life of the cancer warrior. We spend hours doing research, often late into the night, when sleep eludes us. Days are filled with the large and small battles we must fight to have any chance of winning the war on the cancer that is attacking our children. It seems as though not one moment is empty of thoughts and action against this disease.

But the reality is that many of our child warriors don't win this battle. The tumultuous days of fighting childhood cancer end, in the most final way possible.

When our children pass away from this awful disease, the world comes to a standstill in so many different ways. The pain of the empty chair can be amplified by the absence of the daily routine of medication, treatment, research and care that consumes our lives while our children are still fighting. Many bereaved parents have spoken about the hours that stretch before them after their child has died from cancer – the long empty hours where there is no urgency, no watching the clock, no keeping track. A devastating emptiness.

As bereaved parents, we face a long and difficult journey grieving our children, and it is a lonely one. In many ways it can only be a lonely one because each person's grief is unique to them. But we've learned over time, by simply being with other grieving parents, that we don't need to be completely alone in our grief. Yes, it's a lonely time, but not one that must be endured alone.

Rainbows and Smiles in South Africa is run by parents who have experienced the



Above: Catherine Klopper, mom to Henry who died from DIPG in 2016, speaks about her experience



Above: Rainbows and Smiles founder Bonita Suckling, pictured with a photograph of her son Jed, who passed away from a brain tumour.



Above: Connecting on shared experiences and forming new friendships

unimaginable, and who have experienced the reprieve that the company and compassion of fellow bereaved parents can bring. Inspired by the many people, particularly bereaved mothers, who have supported us in our own grief journey, we approached our sponsors to support a Day of Remembrance for 20 bereaved mothers in Johannesburg, South Africa, in November 2016.

The day was set aside as a safe and sacred space to give these mothers an opportunity to meet other bereaved moms, and, most importantly, to remember their children, together. As bereaved mothers ourselves, we





**Above:** Bereaved moms take a quiet moment to write a love letter to their children



**Right:** Bonni Suckling, founder of Rainbows & Smiles, and her mom and aunt, looking at old photos

understand what a beautiful gift it is to be able to freely speak our child's name without needing to be concerned about other people's level of comfort. And so we wanted to create the same opportunity for our fellow bereaved moms.

The event was held at a beautiful hotel and spa in Johannesburg, with a lovely garden area dedicated to the mothers as they enjoyed snacks, drinks and caring conversation. Many were known to each other from social media and other virtual support platforms, and yet most of them were meeting in person for the first time. A makeup artist was on hand to provide mini-makeovers for the moms who also enjoyed massages from the hotel.

What to outsiders was simply a 'moms' day out', had in fact become a sacred space where we could laugh freely, cry openly, and share our experience, our stories, and most of all, our children, with each other. In poignant moments, each mother was given the opportunity to have a photograph taken professionally of her holding a picture of her child – for some it was the first time they had ever had that opportunity since their child died. It was both beautiful, and sad.

Two speakers from The Compassionate Friends (a charitable organisation which provides support to bereaved family members who have lost a child or grandchild at any age through any cause) joined us at the event. They were fellow bereaved mothers who spoke of their



**Above:** Love letters from moms to their children were tied to gold balloons and released

**Right:** Gift bags and gold helium-filled balloons await the bereaved moms

own personal experiences with grief. One mother had used art to express her grief, and shared with us some of the art works that she had created, and what the process allowed her to uncover about her grief journey. The other mother, a counsellor for The Compassionate Friends, shared her experience of enduring the festive season without her child, and shared suggestions on how the bereaved mothers in the room might do the same.

Rainbows and Smiles handed out carefully selected gifts to each guest →



gifts aimed at acknowledging the pain of our children having died, and aimed at encouraging us to remember them openly and freely. Each mother was given a gold-ink pen and gold paper, on which the words "My beloved child..." were printed. They were encouraged to take a little time for themselves and write a love letter to their child on the rest of the page. Each letter was attached to a helium-filled golden balloon, to be released into the sky.

For a few hours on that day, we were given the opportunity to feel completely normal in our grief, and in our pain. We were free to experience and share the complexity and contradiction of life after the death of a child. Most of all, we were able to remember our children in a very tangible and visible way, and express our enduring love for them once more. ■



Above: Delicious food was generously sponsored by a leading hotel group

## Lunch is served - the Perth community marks International Brain Tumour Awareness Week in Western Australia

WEDNESDAY, 26 October 2016 brought a clear blue sky above the Solaris Care Community Garden at Western Australia's Sir Charles Gairdner Hospital (SCGH) that provided a warm and embracing venue for over 100 people from within the Perth, Australia brain cancer community who attended a lunch during International Brain Tumour Awareness Week.

A welcome address by the lunch's host, Professor Anna Nowak (University of Western Australia and SCGH neuro-oncologist), included information on current clinical trials and international treatment standards.

The lunch was coordinated by Diana Andrew in loving memory of her life partner and husband, Jeff, who died in March 2015 just five months after being diagnosed with a highly aggressive brain tumour. Tracey Williams, a research assistant to Professor Nowak at SCGH, also assisted.



Above: Guests at the International Brain Tumour Awareness Week lunch organised by Diana Andrew in Perth, Australia, show off the paper cranes they made during the event.

Those who attended the International Brain Tumour Awareness Week lunch included: committee members from local support advocacy group Brain Tumour Association of Western Australia; John Crofts, representing the James Crofts Hope Foundation; and music students from Swan Valley Anglican Community School who provided lovely entertainment with

the support of head teacher Jessica Andrew (Jeff Andrew's sister). Catering, sponsored by Diana Andrew, was provided by the hospital campus venue Coffee Anatomy.

This year's lunch had added community involvement with the attendance of the city of Melville's Brain Marshall. Brian spoke about Melville's 1000 paper cranes brain cancer community picnic which he and others were planning for March of 2017. He and his colleagues even patiently shared their paper crane-making skills which brought a warmth and creative element to the lunch.

Those touched by brain cancer carry a sadness in their hearts only recognised by others from within the brain cancer community. The lunch provided a chance to come together in friendship and in loving support of each other during International Brain Tumour Awareness Week. ■



# Heart over grey matter – the Brain Tumour Society (Singapore) 2016 brain tumour awareness campaign

Melissa Lim, President  
Brain Tumour Society (Singapore)



Above: Guest of honour, Dr Janil Puthuchear, Minister of State, Ministry of Communication and Information and Ministry of Education, with the BTSS President, Melissa Lim (right) and BTSS Vice President Dr David Low (left) flagged-off the supercars. Photo Credit: MVF Studios



YOU would have heard about the common saying 'Head Over Matter' which exhorts us to be level-headed in handling our situations. As a welfare organisation

concerned with befriending and supporting brain tumour patients in their challenging journeys, Brain Tumour Society (Singapore) or BTSS, adapted this saying to 'Heart over Grey Matter' as the awareness campaign slogan of our third Brainy Car Rally. The message we wanted to convey was that BTSS stands for the 'heart' qualities of courage, love and perseverance that are important in overcoming 'grey matter' challenges.

## Harnessing the power of social media

The Heart over Grey Matter initiative started on 1 October 2016 with a social media campaign driven mainly through our Facebook platform and complemented by a weekly Instagram competition. We posted at least one Facebook entry every day leading up to the campaign finale on 6 November 2016 which was BTSS' third Brainy Car Rally. The posts with the greatest reach were videos on patients' and volunteers' stories which struck a chord in the hearts of many in the social network. In our concurrent Instagram campaign, we invited our supporters to post pictures and share them with others ➤



using #heartovergreymatter. In addition, we managed to draw strong media interest to our brain tumour cause with neurosurgeon Dr David Low, who is also BTSS Vice President, set up for interviews with selected BTSS beneficiaries on TV, radio and in various newspapers.

### The Brainy Car Rally – a wheely great event!

This 2016 Brainy Car Rally was special as it was the first featuring a live performance by our paediatric beneficiaries of the BTSS Kids Programme. Since March 2016, these 13 paediatric beneficiaries and their siblings rehearsed diligently for their finale day performance. They sang an original song *Right Here for You* which was composed by Mario Ferraro with lyrics written by the BTSS President, Melissa Lim. In addition, our shy but courageous beneficiaries danced to the catchy tune of Katy Perry's *Fireworks*, which was received warmly by their proud parents, appreciative supporters and members of the public.

We were entertained by yet another brain tumour survivor, Jeremy Pei, who is also an award-winning magician. Jeremy shared his brain tumour story as he performed his fascinating tricks which left all in the audience thrilled and enthralled.

BTSS was also privileged to have two teams of dedicated volunteers organise and implement our public engagement activities for our 2016 Brainy Car Rally. One was a Brain Tumour Awareness cum Instagram photo booth where we sold our 'Heart over Grey Matter' caps.

The other was a Cranium Challenge which required the participants to examine an installation in the shape of a brain to find clues to a quiz on brain tumours.

### 30 Lamborghinis on show

Of course, the convoy of 30 Lamborghini cars remained the key highlight of our third Brainy Car Rally in November 2016. The spectacular line-up of supercars in the driveway of our venue sponsor, Suntec City Convention Centre, drew big crowds who stopped to look and snap pictures.

A rousing flag-off by our guest of honour, Dr Janil Puthucheary, Minister of State, Ministry of Communication and Information and Ministry of Education, with the BTSS President and Vice President, sent off 30 beneficiaries in style to spread our annual message of brain tumour awareness.



Top left: The Brainy Car Rally in Singapore makes for a very impressive sight! Photo Credit: MVF Studios

Top right: A great day was had by all – adults and children alike. Photo Credit: MVF Studios

Above: Paediatric beneficiaries of the BTSS Kids Programme sang an original song *Right Here for You* which was composed by Mario Ferraro with lyrics written by the BTSS President, Melissa Lim. These amazing beneficiaries also did a dance routine to the catchy tune of Katy Perry's *Fireworks*. Photo Credit: MVF Studios



For me, this third Brainy Car Rally was especially significant as we had much stronger participation from many more brain tumour patients and families who contributed enthusiastically in their own special ways. The engagement activities also helped us involve the public in more fun and meaningful ways. As always, I am grateful to our dedicated volunteers and corporate sponsors, including the drivers from the Lamborghini Club, who have supported BTSS in our annual awareness campaigns since 2014. ■

**Above:** The 'Cranium Challenge' quiz was very popular.

**Right:** Social media presence played a big role in raising awareness of brain tumours as part of the 'Heart over Grey Matter' campaign.

Photos above and right are by MVF Studios



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# An interview with Professor Monika Hegi

*Monika Hegi is Associate Professor for Translational and Experimental Neuro-Oncology at the Lausanne University Hospital (CHUV), Lausanne, Switzerland. Her pioneering work - MGMT Gene Silencing and Benefit from Temozolomide in Glioblastoma - was practice-changing the world over and she continues to work in the field of clinical and basic cancer research, focusing on multidimensional molecular profiles of gliomas.*



Above: Professor Monika Hegi. Photo © Gilles Weber SAM

**IBTA: Where did you spend your childhood?**

**Monika Hegi (MH):** I grew up in Switzerland and the southern part of Germany.

**IBTA: Did you come from a family environment that had a connection with medicine or research?**

**MH:** Not really. My father was an engineer. But an older and a younger brother are both in medicine.

**IBTA: What attracted you to research and later to the brain tumour area?**

**MH:** I was always interested in the underlying mechanisms in biology, and started my research in molecular toxicology and molecular carcinogenesis. When studying one of the first tumor

suppressor genes, TP53, I got involved in brain tumours. Studying the function of TP53 in gliomas brought me into contact with the clinical aspects of cancer research.

**IBTA: Your work is focussed on the molecular analysis of brain tumours. What particular challenges do you encounter in this field?**

**MH:** A big challenge is to get the tissues from patients treated in clinical trials that are the most interesting to study. This is in part due to increasing regulations and paperwork.

In recurrent disease little is known about the changes induced in the course of tumour progression or induced by therapy, so rational choice for second-line therapy is difficult.

An important issue is the high costs for the analyses of “omics” (i.e. genomics, proteomics, metabolomics).



**IBTA: What would be the top three things on your wish list for brain tumour research, particularly with regard to the work that you do?**

**MH:** I would say:

1. Integrate molecular markers for targeted treatments early in clinical development
2. New treatment approaches that are rationally promising also for brain tumours
3. Streamline regulatory issues across countries

**IBTA: What, to date, has been one of the most defining moments of your scientific career in the field of brain tumours?**

**MH:** I realized that close collaboration between basic researchers and clinical researchers is essential in order to translate findings from the bench to the bedside. Otherwise research remains interesting but does not translate into being relevant. I became aware of this when we studied MGMT in clinical trials and the marker was immediately implemented as a stratification factor in all subsequent clinical trials. However, MGMT was already studied decades before as a potential resistance factor for alkylating agent therapy.

**IBTA: Do you anticipate any significant breakthrough in brain tumour therapies in the next ten years? If so, in what area?**

**MH:** I hope so. It has become clear that the magic bullet does not

exist. Therefore I think it will be rational combinations of therapy, based on the molecular and phenotypic make-up of the tumour. The challenge is how to efficiently identify and test such active combinations, and how to take into account that tumours change over time and in response to therapy, likely requiring a change in the treatment strategy. This will require non- or minimally-invasive technologies that can monitor those changes. This is quite a challenge in brain tumours, as the blood brain barrier hinders the release of markers into the blood.

**IBTA: What can patient organisations do to help brain tumour patients and caregivers understand the importance of molecular mechanisms in terms of providing a more personalised approach to their treatment?**

**MH:** The novel treatment approaches and their rationale become more and more complex in the field of brain tumours, also for the treating physicians. It is important to help with providing the necessary information to patients in a digestible form and also for physicians to be able to answer questions.

**IBTA: How do you relax? Do you play music, go for walks, sail a boat? Do you have a hobby?**

**MH:** To relax and change ideas I do hiking or snowshoeing. The Lake Geneva area is perfect for that. Other hobbies are traveling the world. ■

## Step right up and meet the amazing AN Warriors!



MEMBERS of the Facebook group, AN (Acoustic Neuroma) Warriors, walk individually to raise awareness of brain tumours and then combine the number of steps they have taken over a period of time and award certificates to each person completing awareness-raising steps each week, nominating one person as "Walker of the Week". People mainly walk at shopping malls or around their homes or while in hospital.

Suu Blundell, a member of this group based in Australia wrote: "Our small gang of Acoustic Neuroma Warriors has been logging and tallying our steps every week."

Suu added: I'm so happy to report that it's working to help focus on something other than the negative post-op side effects of having one of these tumours. The group seems to be having more fun than before we began! We decided to walk any day we were up to it and have found that it's given a few of us a reason to get out of bed.

It's also taking our minds off doctors visits, MRIs, and our wonky heads. Thank you, IBTA - you've made that all possible."

From 1 January 2017 to 12 February 2017 AN Warriors walked 4,017,579 steps – the equivalent to 3061.39 kilometres or 1902.26 miles. And in one week alone, in March, the group logged over one million steps!

The AN Warriors Facebook page is here:

<https://www.facebook.com/groups/ANWarriors/> ■

### Meet the AN Warriors:



Suu



Bob



Brenda



Zonia



Cindee



Danielle



Lauren



Maria



Matt



Maureen



Sheila



Susie



Angie



Tony



Tracy



Diane

# I'm so proud to be able to help brain tumor patients and their families

An interview with neurologist Dr Jaap Reijneveld, Chair of the Brain Tumour Group Quality of Life Committee at the European Organisation for Research and Treatment of Cancer (EORTC)

Amsterdam, The Netherlands

**IBTA: Jaap, where did you spend your childhood?**

**Jaap Reijneveld (JR):** I spent my childhood in a little village 30 kilometers south of Amsterdam, as the youngest of five in a farmer's family. My parents had a dairy farm, but did not expect any of us to take over the farm when they retired, as it wasn't their first choice either. My father's father died during World War II, and as he was the only son with seven(!) sisters, he did not have much of an alternative choice from taking over the family farm in those dark years. To prevent us from becoming farmers, my parents sent all of us to university, although they didn't particularly like me aiming for medical school as there was a lot of unemployment in that field in those days. At the time of my graduation, however, things had changed dramatically and I have never had any difficulties finding a good job.

**IBTA: Did you come from a family environment that had a connection with medicine or research?**

**JR:** One of my brothers also studied medicine at that time (he is now a professor of public health). I was attracted by the combination of biomedical and social science, challenged by understanding diseases but also by understanding people. I decided to specialize in neurology as I was drawn by the fact that neurology is an island of logical reasoning in an ocean of confusing medicine: through adequate history-taking and neurological examination, it's almost always possible to come to a diagnosis, and ancillary investigation merely serves as confirmation of your hypothesis. In fact, in some ways, it is not very different from an electrician sorting out why the lights went out.



Above: Jaap Reijneveld, M.D, Ph.D. neurologist at the Department of Neurology at VUMC Cancer Center, Amsterdam, The Netherlands

I was able to get a position as a neurologist-in-training at Utrecht University Hospital, where I met Professor Martin Taphoorn, also a neurologist, who introduced me to the field of neuro-oncology. From 2005 onwards, I have had a position as a consultant in both university hospitals in Amsterdam (the most beautiful city of the world!) where I live with my partner and our three adopted children.

**IBTA: What attracted you to medicine and later to the brain tumor area?**

**JR:** It's an understatement to say that brain tumor patients have real problems. They have a combination of a fatal cancer and a devastating brain disease, requiring health care professionals like me to provide the best care possible. We work extremely hard to do this, and to address the challenges presented by the medical and other

needs these people have. I am extremely happy that in our hospital we have a very multidisciplinary team that really supports our patients. It takes a lot of effort to organize this in an optimal way. But it's worth the effort and it makes me proud. Furthermore, we organize things in such a way that not only is the care optimal, but there are also opportunities for clinical and translational research created, and this makes me even more proud.

**IBTA: What particular challenges do you encounter in treating brain tumor patients in your country?**

**JR:** Health care in The Netherlands is organized quite well, guaranteeing all people access to medical facilities. One of the challenges for neuro-oncology is that, in my view, care for these people should be concentrated in fewer hospitals. Currently, some of the smaller centers in our country treat fewer than 50 new glioma patients a year, and I don't think that is good. It's not about 49 or 51, but in particular it's about postoperative treatment getting more personalized during recent years. Structured follow-up and adequate and fast decision-making at recurrence requires an experienced multidisciplinary team with a clear focus on neuro-oncology, which is more difficult when patient numbers are lower. Another challenge for neuro-oncology in The Netherlands is not very different from other countries: the access to new drugs, both at an experimental stage (brain tumors are generally not the pharmaceutical industry's top priority) and afterwards (reimbursement can be an issue). Apart from that, I think that every glioma patient in The Netherlands receives good quality care which is along the lines we - as



Above: Jaap and his partner, Roy, with their three children - Max, Laura and Amber - during a skiing vacation in Austria in 2016

the Dutch Society for Neuro-Oncology in collaboration with patient organizations - defined in our "Quality criteria for diagnosis and treatment of glioma patients".

**IBTA: What would be the top three things on your wish list for brain tumor patients and their families?**

**JR:**

- (1) A breakthrough and a real cure combined with
- (2) adequate cognitive rehabilitation and
- (3) optimal care for the caregivers

**IBTA: You have an interest in cognitive disturbances, quality of life and end of life issues for brain tumor patients as well as being a great proponent of supportive care and survivorship. What special challenges do brain tumor patients (and their families) face regarding these areas that might be unique to their neuro-oncological disease?**

**JR:** Unique for brain tumor patients is that they have a fatal cancer and a devastating brain disease. So, different from patients with other types of cancer, the 'organ' that defines who they are and how they cope with problems in their life, namely their brain, is progressively being damaged, preventing them from staying who they were and coping in the best way they used to. This combination of a fatal cancer and progressive brain disease makes

life for them, and even more so for their caregivers, extremely difficult.

**IBTA: How do you cope with the emotional and psychological challenges to you personally arising from your work?**

**JR:** The only way I am able to take care of my patients in a sustainable way, is

with the help of our specialized nurses Claudia Nijboer and Alieke Weerdesteijn, my fellow neuro-oncologists Tjeerd Postma and Mathilde Kouwenhoven, and the rest of our dedicated Brain Tumor Center Amsterdam team. And even with such a great team, every now and then things can be challenging for me, but I have the great luck to be supported by my partner and our three beautiful children.

**IBTA: Do you anticipate any significant breakthrough in brain tumor therapies in the next ten years? If so, in what area?**

**JR:** Turning brain tumors into a chronic disease would be an enormous achievement, but at this point in time the perspectives are not very optimistic.

**IBTA: How do you relax? Do you play music, go for walks, sail a boat? Do you have a hobby?**

**JR:** Family life is busy with three children aged two, six and eight years, but it also is very rewarding and relaxing. Apart from that I like to go to the gym at least twice a week, go skiing at least twice a year, and catch up with friends and family as frequently as possible. I used to be a free-style skater, but am getting too old for that... ■

## From the IBTA Album...



Above: In October 2016, The IBTA attended and exhibited at the European Association of Neuro-Oncology (EANO) conference in Mannheim near Heidelberg, Germany. Pictured at the IBTA booth are (left to right): Dominique David of ARTC Sud in France; Professor Wolfgang Wick (Chairman of the Department of Neuro-Oncology, Heidelberg); IBTA Chair Kathy Oliver; Dr Stuart Farrimond, IBTA Advisor and Editor of the IBTA's monthly e-News.



# The CERN Foundation Outcomes Project: impact of ependymoma in adults and children

Alvina Acquaye, Research Associate

National Institutes of Health, Bethesda, Maryland, United States

AN ependymoma is a rare type of primary brain or spinal cord tumor. It occurs in both adults and children. To better understand the impact of an ependymoma diagnosis and subsequent treatments on patients, their families and the community, Teri Armstrong, Ph.D., is leading the Ependymoma Outcomes Project for the CERN Foundation. I am also a team member for this project and am a Research Associate at the US National Institutes of Health. I fulfill the role of project coordinator for the Outcomes Project and have been involved since its inception.

The Ependymoma Outcomes Project is an online survey for adult and pediatric ependymoma patients, and the parents of pediatric patients. The project, in its fourth year, has had 280 adults and 79 children and their parents participate. The project provides insight into what life is like for people with ependymoma before, during and after treatment. In a recent article titled, "Clinical Presentation and Outcomes for Adult Ependymoma Patients," that was published in *Cancer* in the autumn of 2016, it was reported that there are significant symptoms and functional impairments as a result of the diagnosis. These symptoms and impairments occur even when the patient has completed active treatment and throughout the trajectory of the disease. This was the largest report to date of the impact of ependymoma in adults.

Here are some of the most compelling results of our survey to date.

## What we have learned about adult patients

An ependymoma can occur anywhere in the brain or spine and can impact patients both physically and emotionally. In the survey, and surprisingly, 33% of patients were unsure of the grade of their tumor, highlighting the potential lack of education



Above: CERN Members at the 2016 Ependymoma Awareness Day butterfly release. Left to right: Sonya Roberts, Teri Armstrong, Samuel Payen, Elizabeth Vera, Alvina Acquaye, Kristin Odom.

related to the disease and implications for follow-up. Interestingly enough, 17% of patients reported seeing a family physician in follow-up for their ependymoma, and not a neuro-oncologist or cancer specialist, making the need to improve our knowledge and understanding of this disease a focal point for future work.

Depending on the tumor location, there was a big difference in the time patients reported symptoms prior to being diagnosed. We found that nearly 60% of spine tumor patients versus less than 30% of brain patients were symptomatic for more than a year before diagnosis. This delay in the time to diagnosis for those with spine tumors is concerning. It is not clear from the study if patients delayed in seeking care or if there was a delay in the health care team ordering imaging studies based on the type of symptoms that patients had. Having a clear understanding

of the differences between locations can prove to be a resource for health care teams treating adult ependymoma patients. With help from medical providers, patients can detect symptoms faster, leading to an earlier diagnosis.

Patients with tumors in both locations experienced a number of symptoms caused by their tumor location, but spine tumor patients reported more symptom burden, or higher severity of the symptoms despite tumors in the spine being lower grade and less likely to be treated with additional treatment besides surgery. Patients with ependymoma involving the spine, also were more likely to report symptom interference with life activities, including walking and general daily activity, regardless of disease status.

Brain and spinal cord tumor patients' symptoms impacted their work responsibilities, with 47% of patients who



**Above:** Alvina Acquaye and Dr. Terri Armstrong presenting a poster at the 2012 Annual SNO Meeting

completed treatment and reporting having stable disease, or disease in remission, being unable to go back to work. This was a surprising and telling result, as most adult patients with low-grade disease live a long life post-treatment, so not returning to work may impact their well-being.

We have also discovered that there is a large percentage of adult ependymoma patients who continue to have symptoms even though they have completed treatment and their disease is stable or in

remission. Survey results showed almost a third of adult patients are on pain medications or narcotics, and about 30% report feeling depressed.

### What we have learned about pediatric patients

Children with ependymoma face unique challenges compared to other children with different types of brain and spine tumors because of the biology of the disease.

Survey results showed that a smaller percentage have significant symptoms and social integration issues, but who, and whether the issues are long-term are still to be determined. Survey results also showed that parents of pediatric ependymoma patients report higher levels of sadness and anger in their children with ependymoma than the children themselves report. It will be important to understand whether children do not recognize their feelings or if parents may also be experiencing feelings of sadness and anger and perceive higher levels in their children, too.

### We still need to learn more...

We want to learn more about the long-term effects of surgery and the location-specific symptoms patients experience, regardless of disease status. We are only given a one-time view of this information from the patients' perspective and having more data across the trajectory of the illness may help in improving patient care and overall well-being.

I am proud to be a part of this project and hope it will have a positive impact on ependymoma patients. ■

### How to participate in the CERN Foundation's Outcomes surveys:

These surveys are ongoing. The CERN Foundation encourages your participation to help them use this information to improve patient care. For further details about ependymoma and how to participate in these Outcomes surveys, visit [www.cern-foundation.org](http://www.cern-foundation.org).



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# Residual Issues

## Parking lot sympathy and sequelae

Bethany Karn

Maryland, United States

WE were out of milk. I added that to my long list of errands and appointments, set my mind on autopilot and drove off. Pulling into the grocery parking lot, I passed a man with a cardboard sign. In shaky black Sharpie ink it read:

*Clean and sober  
Homeless and disabled*

He didn't look like the part. Dressed in a new wool sweater and button down shirt, he seemed more high school math teacher than beggar. In fact he was reading a book - such a rarity! I figured that was the reason for my double take.

Normally I would move on, sad for his plight but ready to avert my eyes. Lots of people beg outside this grocery. There is a shelter in the next block where they can eat and shower and frankly, the parade of sad people makes me weary. But this time, I backed the car up to read the smaller print on his cardboard résumé:

*Brain cancer survivor with residual health issue.  
Still believes in God's power in strangers to help others  
in need. God Bless.*

I rolled down the window and asked him about his tumor.  
"What kind? Where?"

People hoisting bags into their cars turned, surprised, as was I, by my confrontational tone.

He shut his eyes and wrinkled his forehead, straining to remember. He had the leathery sunburn of someone living long stretches outside.

"Ah heck, it's so long....gilo...giblio...."

"Glioblastoma?" I asked.

He smiled and nodded: "Yes, yes! That's it!"

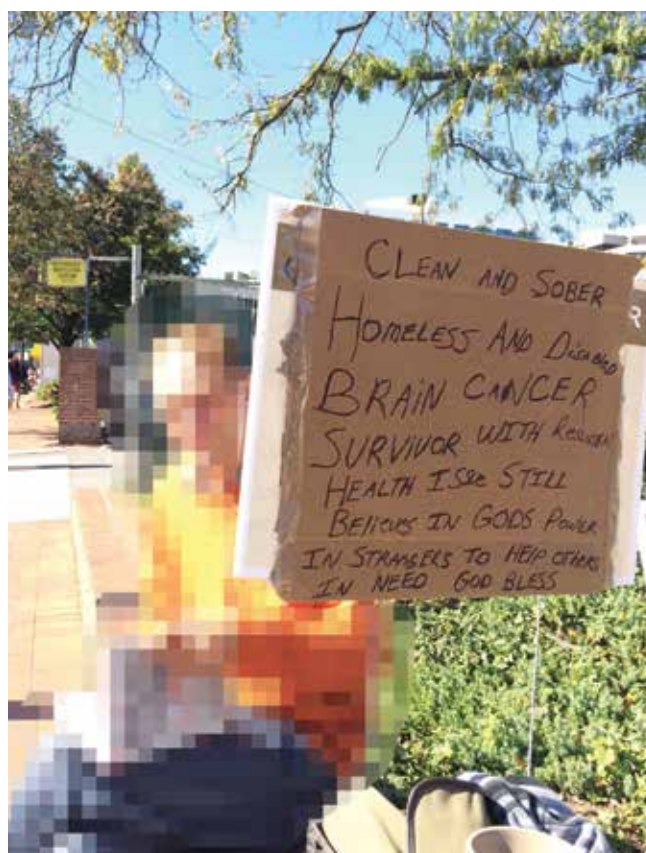
He offered to show me his scar at the back of his head but I knew what it would look like - five or so inches of tight raised flesh in a criss-cross pattern, at the base of the skull or close by, depending on the tumor site. Just like my daughter's.

I emptied my wallet and handed him a wad of bills and all the spare change I could find.

"My daughter..." I started to tell him but even now, ten years after her surgeries, my throat still constricts and it's hard to get the words out. He nodded again and looked down.

"How's she's doing?" he whispered.

"Oh, she's fine,"



Above: The Man With the Cardboard Sign. [Face obscured for privacy as, being homeless, the man was untraceable after this photograph was taken by the author.]

I wiped away tears, embarrassed. Obviously she's not reduced to begging on the street but I suspected that he knew the real score. My daughter and Mr. Clean and Sober are members of a secret club, survivors of life-saving miracle surgery - alive and well - but also, not quite.

I cleared my throat and tried again. I pointed at his sign.

"She also has residual health issues...she can't... she..." My vocal cords continued to seize.

"Can't concentrate?" he offered.

I bit my lip and listened as he ran through the checklist of everything my daughter has endured for ten years.

"Insomnia? Anxiety? Depression? She doesn't drink, does she? Cuz that won't help, believe me..."





He gave me advice on medications to help her focus. He made me promise she wouldn't turn to drink and I white-lied to assure him all was well. I could have told him that her doctors also sternly warned her from drinking while on a cocktail of anti-anxiety and mood stabilizers, but I bet he wouldn't be surprised to learn how poorly this plan plays out in the reality of college life - or just how vulnerable a girl on medication becomes after even a single beer. For a fleeting moment I saw a sunburnt version of her sitting on the curb with a sign of her own. I shut my eyes to snuff out that particular vision. No, I promised myself, I won't let that happen. Not on my watch.

I asked if he knew where the homeless shelter was and he said he did. He thanked me for the money to buy lunch. I promised I would be back to check on him.

"God bless," we both said, six or seven times.

Somewhere in the dairy section it dawned on me. I had just gotten more practical advice and compassion from a disabled homeless man in a parking lot than I have in ten years of taking my daughter to follow-up visits. There's no denying that she is a medical textbook happy ending. Her brilliant team of surgeons and nurses labored for hours to give me what I prayed for a decade ago: a tumor-free, healthy, living child. But all that time I have wondered - do any of us understand what she is living with?

At follow-up visits I would ask if we should worry that her grades had nose-dived; that she wouldn't or couldn't stay ➤

Left "Roof" by Sonja Plungis who is a brain tumor survivor and Bethany Karn's daughter

Below: "Head Games" by Sonja Plungis







Above: "Head Aches" by Sonja Plungis

organized enough to do her schoolwork. Wasn't it odd, I asked, that her handwriting had reverted to chicken scratch? Why was she crying at the computer keyboard, admitting through tears that it took "so long to think" that she couldn't write a simple email to her friends?

There were other questions too, balled up in a lump in my throat, that I couldn't begin to ask, like why was she so volatile - angry then weepy, glaring at everyone, even her friends, testing their patience until there were suddenly no more friends to glare at. I didn't ask because I had no idea how to tease apart what was tumor-related and what was an ugly adolescent episode. Not the kind of question I felt, at the time, which deserved the attention of world-class neurosurgeons.

The questions I could ask were met with polite concern, a pat on the shoulder, a shrug. It was not their department. I understood that. I really did not expect a neurosurgeon to hold the hand of a teen going through a rough patch. But what I didn't - and still don't - understand is why no department like this exists at all; no place to talk through the mental fog that frustrates so many brain tumor survivors, no check-in point to see how they're coping, or not, with everyday life.

Instead, we had to help our daughter find ways to cope with issues we couldn't quite put our fingers on. Was it depression? Bipolar? Bad parenting? In between therapy appointments I looked up the definitions of words never once uttered by hospital staff: sequelae.

Instead I had to stumble upon an April 6th Washington Post article that rang so true I choked on my morning coffee. We were not alone. Children recovering from all kinds of invasive surgeries are showing signs of residual issues that will not go away. Should we be concerned about this? Did anyone in our growing sphere of doctors and therapists know anything about this? The pained silences and shrugs led me to believe I was just grasping at straws.

Instead I had to book an appointment at the asphalt office of a sunburnt man who dispensed validation and empathy - all for the co-pay of the sticky spare change in the bottom of a mini-van cup holder. It was an empowering message to hear and see the simple truth I had long suspected: the sequelae are as real as the tumor and almost as dire. There are long-term, post surgical consequences that - while not as deadly as a growing tumor - can, if unchecked, completely derail a life.

In the check-out line at the grocery store I resolved to no longer take shrugs for answers. The next medical expert who minimized our concerns I would refer to Dr. Clean and Sober, a man who, in a fairer world, ought to lead medical school seminars entitled "Residual Issues and Object Lessons".

But of course it's not a fairer world. Neither he nor my daughter's experience will merit further notice - not until some clever someone figures out how to make money off of post-surgical sequelae. Until then, he'll be a Clean and Sober man



Above: Bethany Karn (right) and her daughter Sonja Plungis (left)

with a sign, she'll be a young adult Sisyphus rolling her issues uphill and I'll be a mom having an existential crisis as I shop for reduced fat milk of human kindness. For me, at least, the truth is still in that cardboard sign, in ways the author may not even have suspected. I hope he realizes he is the Stranger imbued with the power to help others in need. I hope he knows I believe in him.

#### Afterword...

Since first writing this essay, my daughter and I have been lucky enough to stumble upon fellowship and support at Camp

Sunshine (<https://www.campsunshine.org/>), the year-round resort for pediatric patients with life threatening illnesses and their families, as well as the work of tireless researchers and fundraisers at A Kids' Brain Tumor Cure PLGA Foundation (<http://akidsbraintumorcure.org/>). Through this dedicated network we have found sympathetic compatriots, referrals and yes, finally, the milk of human kindness. We cannot thank them enough. ■

This article first appeared on Medium's Health Care in America website. Copyright has remained with Bethany Karn as the author.

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# Cayman Islands brain tumour survivors, families, friends and supporters walked and ran to raise awareness

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ON 19th February 2017, on a very still crisp morning, Brain Tumour Foundation (Cayman Islands) "The Forgotten", hosted its third annual "Walk For Hope" Charity 5K Fun Walk/Run. Heroes Square in George Town, Grand Cayman, Cayman Islands, the capital city of the three islands, was chosen as the most fitting location for such an occasion, for this great cause. The Walk/Run started and finished at the Square.

The participants in this event came from a good cross section of people from all over the island. They included staff from our Health Services Authority (HSA), Cayman Islands National Insurance Company (CINICO), co-sponsors of this event, Cayman National (CNB), TrinCay Medical Services, Royal Cayman Islands Police Service (RCIPS), Minister of Finance, Marco S. Archer, who has been a consistent supporter of this cause, as well as employees of the Cayman Islands Government (civil servants), families and friends of people touched and/or affected by this illness. This year we had people from overseas travel to join us in support of our endeavor and last but by no means least, survivors!



Above: Members of the Brain Tumour Foundation (Cayman Islands) "The Forgotten" organisation. Photo by Miguel Escalante

February is our month of awareness. Proceeds from this event have been used to assist existing patients and some newly discovered patients, also towards raising awareness and our fight to continue educating everyone in the Cayman Islands about brain tumours.

We are very grateful to all those who supported us, either by participating, volunteering, donating tents, chairs, sound and music, and to Foster's – IGA, who for the second year has joined us and co-sponsored this event.

This year we had our biggest turnout, which is encouraging and a sure sign that we



Above: On your marks, ready, get set, GO! People from all walks of life in the Cayman Islands (and even some from overseas) participated in the awareness-raising activities. Walkers started half an hour before the runners. This year there were many more runners than walkers.. Photo by Miguel Escalante



Above: The Hon Minister of Finance of the Cayman Islands, Marco S Archer took part in the brain tumour awareness-raising walk/run. Photo by Miguel Escalante

are reaching the people in our community. Although funds are primarily used to assist the patients, our ultimate goal is to build a neuroscience department here on the island which will enable patients to have all of their surgeries and treatments at home.

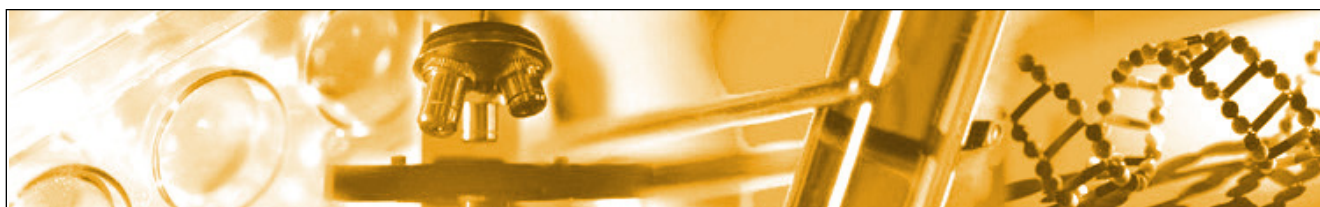
We look forward to a bigger and better event next year. With everyone's continued help, we know this is possible. ■



**Above:** On the day of the Brain Tumour Foundation (Cayman Islands) "The Forgotten" 5K walk/run it was Louise Bailey's birthday but she also walked in honour of her five-year-old granddaughter whom she lost to a brain tumour. Photo by Miguel Escalante



**Above:** Runners in George Town Harbour. Photo by Miguel Escalante



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# As a doctor with a brain tumor, I now truly appreciate the patient perspective

Chris Chiou, MD

Okemos, Michigan, United States

"KNOCK, knock"

I warn of my entrance.

"Come in," the waiting patient replies.

The door opens and I enter, with cane in one hand and laptop in the other. I am obviously unsteady, with each step shakier than the last, almost as if the exam room floor were made of ice. I then extend my hand and say, "Hi, my name is Dr. Chiou, it is an honor to meet you. Thank you for letting me be your physician."

The word 'patient' comes from the Latin word "patientem", meaning "one who suffers". I have been fortunate enough to be on both sides of the examination table, as both a physician and a patient and have come to fully appreciate what it means to be "one who suffers".

On the morning of 20 March 2013 I awoke with double vision. My limited clinical experience convinced me that this was a manifestation of a complex migraine. But when it kept progressing, an MRI was obtained which showed "a 4.5 centimeter mass in the brainstem, possibly cystic, with no evidence of hydrocephalus. Clinical correlation recommended."

I remember crying when I heard the diagnosis; an epidermoid posterior fossa tumor (most commonly seen in pediatric patients). All of my medical training was thrown out the window. "How can this happen to me?" I asked myself. I eat well and exercise every day. At that moment I actually hoped for a diagnosis of multiple sclerosis, a dreadful, debilitating disease.

After a week of frenzied searching and consultations with multiple neurosurgeons, I met with a pediatric neurosurgeon who was referred to me by a family friend. Dr. Cormac Maher is a pediatric neurosurgeon at the University of Michigan, who is known for his experience with epidermoid posterior fossa tumors. I underwent a 16-



Above: Dr Chris Chiou

hour surgery to remove the mass. Before the surgery, I had played four years of varsity tennis at Harvard University, and went on to compete on the professional circuit. I also completed medical school and began a Family Practice Residency. I do not recount my past achievements to boast or brag, but simply to highlight the contrast to my current state.

As I explained to a good friend of mine, I essentially "went from fully functional to disabled overnight."

Since my brain tumor resection, I have pondered much that I hadn't considered before. One of these is the idea of perspective. Now, I wonder about the perspective of the patient. From my perspective, the experience of introducing myself to my patients is straightforward. My nurse tells me that the patient is ready to be seen. I then make my way to the patient's examination room, take a deep breath then knock as I was taught in medical school. I then introduce myself, shake the patient's hand, and thank them for allowing me to be their physician.

It is through each and every encounter

that I truly come to understand and appreciate the patient in this field of medicine. Before my patient encounters, I give all my patients a two-paragraph letter, explaining my own condition. After a patient reads the letter, I enter, hobbling. But as much as I try - just as they can't pretend to know what it's like to go through what I've been through - I can't imagine their perspective. I know that in their eyes, our encounter starts with fear and anxiety. What shape is the doctor in? Can he help me? These questions and thoughts I cannot control but my hope is that by the end of our visit, this fear has turned into comfort, reassurance, and confidence in my ability to address their health concerns.

Before the discovery of this brain mass, my days were filled with diagnosing and managing conditions in other people such as chronic obstructive pulmonary disease (COPD) and diabetes. Now I find myself on the other side, in waiting rooms for appointments with neurologists, physical medicine rehabilitation physicians, and physical therapists.

Before the tumor, a patient to me was simply someone who scheduled an appointment and who sought out my expertise in managing health issues. But, whenever I wait to see a physician now, as the patient I find myself with a mix of emotions. The one constant emotion I experience is fear. "Fear of what?" I ask myself. Fear of the diagnosis? Fear of the management? I finally figured out that this fear was a fear of vulnerability. I had not realized that being a patient meant opening oneself to the doctor. I cannot think of any other profession where such trust is given to another.

One patient may explain their crippling depressive symptoms, while another details their bouts of abdominal pain. This inherent vulnerability is part of the patient-physician relationship. However, within this vulnerability





Above: Chris Chiou and his family (left to right): Cormac (then six months), Fleur (Chris' wife and a family physician), Christian (then six) and Chris

lies the beauty of medicine; this vulnerability is born from trust: trust in the doctor, trust in their training, and trust in their judgment. It may have taken a brain tumor, and for me to become a patient, but I finally learned of this trust given to each and every physician.

The famous Chinese Philosopher Lao Tzu once said, "A journey of a thousand

miles begins with a single step." During this journey, I have had moments when I purposefully tried not to pause and reflect on lessons I have learned. Perhaps I feared that boiling down this ordeal to one overriding lesson might somehow cheapen what I've gone through, or perhaps I have some underlying post-traumatic stress disorder and I fear dredging up these experiences.

But in returning to my clinical duties, I have come to realize that this tumor has changed my own perspective. I have always only considered myself in the role of the physician. This ordeal has given me the rare opportunity to have the perspective of the patient. It is a position of humility, vulnerability, and faith. Unfortunately, it is easy to fall back into the designated "perspective" or role as physician, forgetting the person and what it truly means to be a patient.

My journey, even though different than what I had envisioned, has allowed me to appreciate first-hand the beauty of the physician-patient relationship and truly understand why we must remember to be compassionate and empathetic to our patients. With every visit I have with a patient, I begin a



Above: Chris, prior to his neurosurgery for a brain tumor, together with medical colleagues

new journey, one that starts when I take my first wobbly step into the exam room. ■

Chris currently writes a column for the Epidermoid Brain Tumor Society, as well as for What's Up Doc? (a health literacy website), and also has his own blog at [www.handcappeddoctor.com](http://www.handcappeddoctor.com)

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# I will survive: survivorship and brain cancer

Dr Danette Langbecker, NHMRC Research Fellow  
The University of Queensland, Australia

WE are seeing an increasing number of cancer survivors worldwide, and recognise that cancer survivors may encounter a range of physical and psychosocial problems as a result of cancer and its treatment, even a significant time after treatment has finished. In the past, the main focus for cancer survivors was to detect cancer recurrence, but it is now recognised there is a need to address the physical, psychological, social and practical concerns of survivors to improve their health and quality of life.

At the survivorship stage, we do not know a lot about the concerns of survivors of brain cancers, particularly long-term survivors, because of the relatively low incidence and poor prognosis of glioma. We expect that many brain glioma survivors experience issues beyond those of other cancer survivors, particularly neurologic or cognitive impairments. We also think brain tumour survivors may experience issues not common among other cancer populations due to the fact that many may continue to receive treatment and monitoring over a longer period.

Caregivers of glioma survivors will likely have a number of unmet needs related to the support that they provide, and its impact on their own lives as well. But particularly in the Australian context, we do not have a lot of information to help us focus on what are the most important concerns of people who are living with glioma and the people who support them, over the longer term. This information would be very useful in helping us to create new models and projects that could help address these concerns.

This need is what led to the Australian Brain Cancer Survivorship Study which is an Australian-wide survey of 'long term' glioma survivors and their carers. We are inviting adults aged 18 years and over who have been diagnosed with any type of glioma at least two years ago to participate by completing a survey either via pen and paper, or online.

It was difficult to decide on our eligibility criteria relating to length of time after diagnosis. Cancer "survivorship" is usually defined as starting as soon as a cancer is diagnosed, but practically not usually measured until after treatment finishes. For brain cancer, treatment may not end at a set point, or may stop and be resumed as the tumour grows, so we couldn't define it this way.

We decided that anyone who has lived at least two years after a diagnosis can participate, and we've been particularly excited to see some true "long term" survivors involved, as their experiences can give hope to others.

The survey asks about health and well-being; about issues which



Above: Dr Danette Langbecker

may be affected by having (or having had) a brain tumour such as problems with thinking and memory; one's need for help (eg with physical and practical issues); and psychological well-being. We're also inviting caregivers - defined as a survivor's main provider of physical, psychological or practical support - to complete a survey to tell us about what sort of help they give the patient, the impact of doing this on their lives, and what help they need to keep providing care and support.

We have had a great response from survivors and carers so far, with participants mainly hearing about the study from brain tumour support groups, cancer councils, and via social media. We are hoping to reach our target of 100 brain cancer survivors and 75 caregivers, and will analyse our data in full once this goal is reached. We recently performed an interim analysis involving 28 survivors to present results so far at the combined Asian Society for Neuro-Oncology (ASNO) and Cooperative Trials Group for Neuro-Oncology (COGNO) Annual Scientific Meeting held in Sydney in September 2016.

Of the 28 survivors, two-thirds were male, with an average age of 49 years. Just over seventy percent were diagnosed with a high-grade glioma (most commonly a glioblastoma multiforme, GBM) and most had surgical debulking, radiotherapy and chemotherapy. Among those diagnosed with a high grade glioma, the average time

since diagnosis was 51 months, and among those with a low grade glioma, 60 months, but some survivors, both low and high grade, had been diagnosed more than ten years previously.

The quality of life reported by survivors was, somewhat surprisingly, highest for physical well-being, and lowest for emotional well-being, although this varied significantly across survivors. And although emotional well-being scores were - on average - lowest across survivors, only a small proportion of participants gave scores which we would classify as suggestive for depression (about 21%) or anxiety (about 18%).

A lot of survivors reported problems with thinking or memory to some degree. At least three quarters of participants reported some level of problems with 13 items asking about these issues. The most commonly reported issue was "I have forgotten names of people soon after being introduced", followed by "I have walked into a room and forgotten what I meant to get or do there".

Survivors also provided very useful information about the help they need. Almost half of participants reported a moderate or high need for help with supporting their families, reporting concerns about the worries of those close to them. Almost 30% of participants reported a moderate to high need for help with fatigue, and dealing with uncertainty about the future.

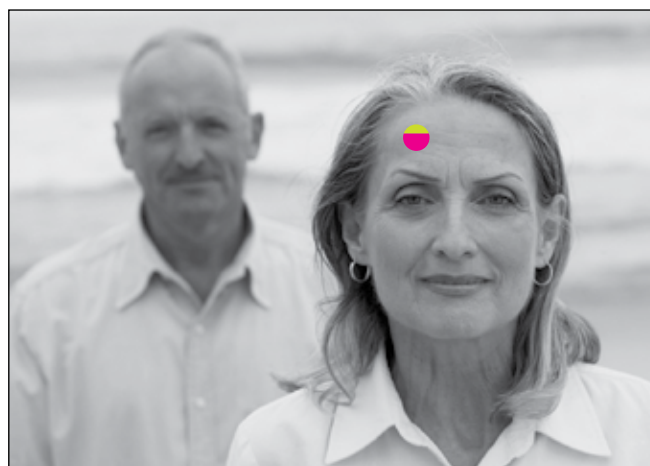
We also asked survivors about what changes have happened to their work and relationships as a result of their brain tumour. We are still looking at these responses, but some people have noted reduced interactions with others, or that their friends have drifted

away, while others have said that their relationships with their families are now more important to them. Although most survivors worked full time prior to their diagnosis, many reported that they do not work following their diagnosis.

The Australian Brain Cancer Survivorship study will be open for participation in the coming months, and we invite all those in Australia who have a glioma and their carers to think about sharing your experiences with us. We hope that the results of this study will guide the development of brain tumour specific survivorship care plans and pathways, and help us to address the specific challenges that survivors and caregivers face. ■

If you would like more information about the Australian Brain Cancer Survivorship study, or to participate (if you live in Australia), go to: <http://survey.qut.edu.au/f/184646/7c13/> or email Danette Langbecker at [d.langbecker@uq.edu.au](mailto:d.langbecker@uq.edu.au)

The IBTA maintains a list of neuro-oncology conferences on its website at: [www.theibta.org](http://www.theibta.org)



## The Norwegian Brain Tumour Association

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

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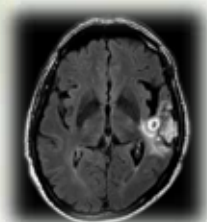


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# The Childhood Brain Tumor Association - serving children with brain tumors and their families in Taiwan

Ying-Hsiu Lin, Childhood Brain Tumour Foundation of Taiwan  
Taiwan (R.O.C)

2016 was the year of the Childhood Brain Tumor Association of Taiwan (CBTA) taking on innovation. In this year, the association continued to serve children with brain tumors and their families, and provided support to our brain tumor community.

Here are some of the activities which took place.

1. Family networking activities, designed around multiple themes of activities for different regions of Taiwan. These activities united children with brain tumors and their families from different regions in order to be able to share information about their experiences.
2. Youth group for children with brain tumors and volunteers' training. We operate a hospital volunteers programme which allows volunteers to help and befriend children and young people with brain tumours so that experiences can be shared and successful treatments celebrated.
3. Youth group summer camp program. The purpose of this program is providing children and young people with group activities that they can participate in as part of school and society. Many activities require team cooperation and group work. Through being part of a team young patients can re-connect and realize that they are needed and loved as part of our society.
4. Hospital story time and holiday festival events. Not only does the CBTA organize its own activities but we also connect to nine other organisations to join together in a "care sharing system". This inspires and enhances our own programmes even more. The clown team brings joy to the afternoon.
5. This year, and for the first time, the CBTA tried to offer counseling services and a "Little Angels" group. The counseling services provide psychological support to help patients' families. The "Little Angels" is a special group for families who are going to say goodbye to their child and for those families who have already lost a child during their brain tumor fight.

Finally, we look forward to 2017 and the continuation of our work and services. We hope that more people will learn about the association and better understand the needs of children with brain tumors and their families, so they can accompany these brave fighters through their difficult years of hardship. ■



Above: Young people supporting each other during a climbing challenge



Above: Success!



Above: Caregivers' meeting





Left: A group of young brain tumor patients playing the Noah Table Game



Left: A youth group engaged in activities for brain tumor patients



Right: "The Clown Team" brings joy to an afternoon in hospital



Above: The National Symphony Orchestra plays for patients, healing body and mind

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“Brain Tumour Support are such a brilliant and helpful charity, my family have seen what a difference they can make!”  
*Catherine*

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  - Advanced brain tumour treatment machinery
  - Brain tumour research centres
  - Access to affordable diagnostic imaging services
- Running campaigns to have all health personnel in satellite clinics sensitized on signs and symptoms of brain tumours

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# The Canadian Brain Tumour Registry Project



International data suggests that Canada has one of the highest incidence rates for brain tumours in the world. Canada has not systematically recorded incidence rates for all primary brain tumours, traditionally omitting non-malignant brain tumours. An estimated two-thirds of all non-malignant brain tumours are not reported in cancer registries and yet they can be just as devastating as malignant tumours. This must change in 2017, which also happens to be Brain Tumour Foundation of Canada's 35th anniversary milestone year.

For years, Brain Tumour Foundation of Canada has estimated that 27 Canadians are diagnosed with a brain tumour each day. This figure is based on data that has been extrapolated from the Central Brain Tumour Registry of the United States (CBTRUS) and applied to the Canadian population. Given international variation in incidence rates of brain tumours, this assumption should be replaced with accurate data. Brain Tumour Foundation of Canada has long advocated for every brain tumour in Canada to be counted, which is why we have started the Canadian Brain Tumour Registry project. Brain Tumour Foundation of Canada is now advocating to complete the funding of this project in 2017 which would bring hope to the thousands of Canadians living with a brain tumour.

Canadians such as Jennifer Gouchie-Terris, who has worked tirelessly to establish Canada's first brain tumour registry. Jennifer's son Brandon was diagnosed with a low-grade pilocytic astrocytoma at the age of four. The location of this tumour, deep inside Brandon's brain made it difficult to achieve a complete resection. After four years of treatment, including surgeries, chemotherapy and radiation, Brandon's disease stabilized and he enjoyed ten amazing years of near-perfect health.



Above: Brandon and his beloved dog

Brandon and Jennifer were shocked to find out that brain tumours were inconsistently tracked in Canada, with some provinces and territories not collecting any data on brain tumour types at all in 1998. Together Brandon and Jennifer helped develop a Private Members Bill that called for the creation of a national registry to capture data on all brain tumours, both malignant and non-malignant. Private Members Bill M-235, which called for





Above: Brandon, then 17, and his mom, Jennifer

the creation of a national standard for the collection of all brain tumours in Canada, was passed by an overwhelming majority in the House of Commons on February 14, 2007.

Sadly, Brandon passed away in October 2012, age 18. After more than a decade, a routine scan showed a new inoperable tumour in his brain. Despite being terminally ill, Brandon asked his mom to continue the fight for better brain tumour data and a national registry to track the disease.

In 2011, Brain Tumour Foundation of Canada invested CAD \$122,000 to conduct a Canadian feasibility study to determine what information already existed and how difficult it would be to correlate this information into one centralized database. Brain Tumour Foundation of Canada hired renowned epidemiologist, Dr. Faith Davis, to lead this project. Dr. Davis has extensive experience in developing a brain tumour registry in the United States called the CBTRUS (Central Brain Tumour Registry of the United States), and after a two-year study, Dr. Davis determined that it was feasible to move forward with Phase 2 of this project – to establish a Canadian Brain Tumour Registry for which Brain Tumour Foundation of Canada is currently seeking funding.

Now that the feasibility study has been completed, the next stage of the project has five goals:

1. Supplement registry activities (British Columbia, Alberta) to obtain data on non-malignant brain tumours (including meningiomas, low grade gliomas, vestibular schwannomas)
2. Create a first Canadian brain tumour surveillance report (from British Columbia, Alberta, Manitoba, Ontario, Quebec) similar to that published by the CBTRUS in the United States
3. Develop approaches to support collaborative research
4. Develop recommendations for the collection of relevant molecular data and tumour classification information critical for monitoring treatment decisions and outcomes
5. Fund a collaborative demonstration project between Dr. Marshall Pitz (Manitoba) and Dr. Jay Easaw (Alberta) which explores clinical case identification and coding for patients on Avastin. This project will provide insight as to the efficacy of this drug treatment for a larger population base.



Above: Brandon and former Canadian Prime Minister Stephen Harper

Why does this matter? Data resources from a Canadian Brain Tumour Registry with readily available case information would help researchers expedite their studies regarding incidence and survival patterns, factors that may cause or prevent brain tumours, equal access to care, and quality of life.

Brain Tumour Foundation of Canada needs to raise CAD \$230,000 in order to complete the five steps outlined above and begin the Canadian Brain Tumour Registry project. But we are not doing it alone. The Canadian Brain Tumour Registry Project has been recognized by Brain Canada as one of the top seven projects in Canada. As such, it was offered matching funds by Brain Canada to complete the CAD \$460,000 project. Thanks to the generosity of the people who have supported this project through fundraising events, Brain Tumour Foundation of Canada is already half way towards completing this funding milestone!

Jennifer Gouchie-Terris continues to advocate for a Canadian Brain Tumour Registry.

“Hope carried Brandon throughout his life but also gave him a sense of peace in the face of death”, said Jennifer. “Now we ➤



Above: Dr. Faith Davis, Research Lead, Canadian Brain Tumour Registry



have hope that someday we'll have a better understanding of the cause of brain tumours and, most importantly, we hope there will be a national registry to ensure each and every brain tumour gets counted in Canada."

Last November, Jennifer and her husband Darren, cycled from Cambodia to Bangkok, Thailand, to raise money for the project. Thanks to the matching funds from Brain Canada, the CAD \$30,000 that they raised will be doubled to CAD \$60,000 to ensure that every brain tumour counts!

We look forward to providing the first report from the Canadian Brain Tumour Registry in 2019. In the meantime, side projects have already started. In the fall of 2016 an article was published in the *Journal of Registry Management* on Pediatric Brain Tumours in Alberta. This case ascertainment came about as a result of the

Canadian Brain Tumour Registry project and talks to the importance of this project: "Incomplete or inaccurate brain tumor data have a direct effect on the ability of a province to accurately assign health care dollars by region, create centres of excellence for treatment, create efficiencies and plan for the greatest needs. The more that is known about the incidence of all types of brain tumors will allow the enormous treatment cost to be planned for, targeted and reduced." ■

Read the full *Journal of Registry Management* article and learn more about this project at [www.BrainTumour.ca/Registry](http://www.BrainTumour.ca/Registry).

## Brandon's inspiration helps ensure every brain tumour is counted in Canada

### 500 km cycle trek significantly boosts funds for the Canadian Brain Tumour Registry project

#### Jennifer Gouchie-Terris

Brain Tumour Foundation of Canada Advocacy Committee Member

"MOM...am I really going to die?"

A question no parent ever expects to hear but one that has echoed through my head time and time again since losing my 18-year-old son to a brain tumour in October 2012.

Brandon was first diagnosed with a brain tumour in 1998 at the age of four. It was a non-malignant low grade glioma at the time but because of its location, treated in much the same way as a cancer diagnosis in that he underwent several surgeries, chemotherapy and radiotherapy.

His disease finally stabilized four years later and he went on to enjoy ten amazing years of near perfect health. I quickly learned that there is a serious lack of consistency in the collection of non-malignant brain tumour data throughout Canada. In fact, some provinces and territories are not collecting it at all which results in significant gaps in brain tumour data.

So, I approached my local Member of Parliament, Bill Casey, and together we decided the best way of addressing the problem was through a Private Members Bill. The result was Private Members Bill M-235 which called for the creation a Canadian National Brain Tumour Registry that would capture data on all brain tumours, both malignant and non-malignant. Much to our delight, M-235 was passed by an overwhelming majority in the Canadian House of Commons on 14 February 2007.

Life was good and the future looked bright. But just weeks



Above: Darren Terris (left) and his wife Jennifer Gouchie-Terris (right) on their grueling but highly successful cycle marathon from Cambodia to Thailand. Funds raised will go to the Canadian Brain Tumour Registry.

into Brandon's final year of high school, he began to exhibit some unusual neurological symptoms. An MRI showed a new inoperable tumour and this time it was cancer. Chemotherapy proved ineffective, leaving re-radiation as the only option. After six weeks of radiotherapy, the mass had virtually disappeared and Brandon was told he was in remission.

But the euphoria was short-lived when, just six weeks later, follow-up imaging showed significant disease progression. Out of viable options and with no clinical trials on the horizon, Brandon refused further treatment and passed away a few months later.

In the fall of 2015, my husband Darren and I attended the second biennial International Brain Tumour Alliance (IBTA) World Summit of Brain Tumour Patient Advocates in Sitges, Spain. I left that summit filled with hope and inspiration and more determined than ever to help make Canada's first and only complete collection of brain tumour data a reality in memory of Brandon and all other victims of the disease.

A family friend had recently taken part in a trek to Machu Picchu through a fundraising organization called Charity Challenge which inspired us to sign up for a challenge of our own. On 27 November 2016, we embarked upon a 500-plus km trek we named "Riding for the Registry" which took us from Angkor Wat, Cambodia to Bangkok, Thailand.

We set our fundraising goal at CAD \$10,000, representative of the 10,000 people estimated to be diagnosed with a brain tumour each year in Canada. But when all was said and done, we managed to raise CAD \$30,000 which was matched dollar-for-dollar by Brain Canada.

One hundred percent of all money raised went to the project but the Brain Tumour Foundation of Canada must raise CAD \$230,000 over the next three years in order to complete the next phase and ensure every brain tumour gets counted in Canada. ■



Above: Jennifer Gouchie-Terris (left) and her husband Darren Terris (right)



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# Driving and travelling after treatment for a brain tumour

Associate Professor Andrew Cole, MBBS FAFRM,  
Chief Medical Officer, HammondCare and Conjoint Associate Professor  
University of New South Wales, Sydney, Australia



A person can only stay at home for so long before they risk developing cabin fever.

Getting out and about to do shopping, see friends, attend medical appointments, and do more adventurous things like going to a football match, seeing a movie, or going on a holiday is a natural part of life for most people. So it is very natural that people want to get going as soon as they can after brain tumour treatment.

## Getting Around Driving

As you may recall from learning the skill the first time around, driving is a very complex task; it needs both hands and feet working well to control a car or motorcycle properly. The driver must be able to do this while looking at the road, and not looking at either feet or hands. As drivers, we drive by responding to what is happening around us, keeping our car's speed and position on the road so as to keep a safe distance away from other vehicles and people. All that needs good sensory input from our eyes, ears and hands and feet, good integration of all that information in thinking and good judgment in deciding what to do next.

At the same time, driving a car is often of great social importance – for some people, it may be a central mark of their adult identity. In many places public transport is so inadequate that people have to depend upon a car of some kind to get around.

There are also legal issues to consider. Whilst the precise details of these vary according to where we live, the basic principles still apply:



Above: Associate Professor Andrew Cole

- driving a car is a privilege regulated by law and is not a universal human right
- there is a triangle of people responsible to ensure safe driving: the person driving the car; medical professionals looking after the person's health and the authorities that issue drivers' licences.

For the driver, the basic question is: "Do I really need to drive a car?" As the primarily responsible person, if there is an accident, the problems sit with the driver. Basically, a driver must acknowledge and report to their doctor and the driver licensing authorities any medical problems they have that might affect driving, which also means that the driver must have insight to recognise when there are problems present.

Health care workers (usually doctors, with associated therapy staff) will ask the question: "Is it safe for this person to drive?"

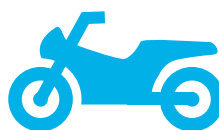
This requires assessing whether the brain tumour has been controlled with treatment and the effects of the disease on the person's physical functional ability; making a judgement if it is (or not) safe for that person to drive; advising the person impartially of that; and reporting to the driver licensing authority if the person is unsafe, or ignores medical advice not to drive.

Finally, the driver licensing authority will ask the question: "Is it legal for X to drive?" The licensing authority obtains information from people and recommendations from their health care workers, applies the legal standards and makes a decision about whether a person meets the criteria to drive safely, or drive with restrictions, or not drive at all, in which case the driving licence is cancelled. Legal sanctions apply if a person continues to drive a car after their licence is cancelled.

After brain tumour treatment, it is vital to know that a person has both the physical and psychological ability to control the vehicle. This requires a full medical and driving history and a complete medical examination and documentation of the primary condition and any other medical problems present. It usually will also require an observation of the person's ability to drive a car under controlled conditions, in whatever way is mandated by local laws.

It is also important to think about whether the driver might be helped with modifying the driving controls in some way, and knowing whether they can understand and apply the rules of the road, especially if new





cognitive changes are apparent. Considering all this means health care workers can discuss with patients and family members a recommendation that a person can drive without conditions, or with conditions and/or modifications to the car, or that they are not fit to drive at all. That will also mean that a further or periodic review will be indicated, as brain tumour biology is often dynamic and things might well change in future.

Some specific problems that will interfere with driving include any occurrence of blackouts or seizures. While the exact rules vary from one country to another, a seizure occurring usually means a person cannot drive for at least six to 12 months, and only then can they start to drive again if they are taking medicines to prevent a recurrence. Because a seizure may lead to complete loss of motor control and usually of consciousness, untreated and uncontrolled epilepsy is clearly incompatible with safe driving. Loss of visual field perception in any place clearly will usually preclude driving.

Finally, it is almost never considered safe to return to driving a commercial vehicle (truck, bus, taxi or large van), airplane or train, after treatment for a brain tumour. When loaded, these vehicles are larger and heavier than the usual car, so can cause much more damage in a collision, and multiple other innocent passengers may be injured - or worse.

For all these reasons, a full and careful assessment of every person who wishes to return to driving a car or motorcycle after treatment for a brain tumour is mandatory.

### Travelling long distances

After diagnosis of a brain tumour, the question of long-distance travel, frequently by air, may arise. A person may wish to travel to see their family or places that are far away.

For surface travel by bus or train, the access questions might include considering whether the person with a brain tumour will be able to get through the check-in processes at the station, and climb up into

the bus or train, and get to their seat. Are there toilets that the person can get in and out of during the travel, and if there are problems, can a family member or carer travel with the person with a brain tumour?

For air travel, the airplane is essentially a flying bus. At the start of travel however, the documents needed and the check-in processes are much more complex than for train or bus travel. Travellers have to go through security screening scanners and other checking processes, and the walking distance between check-in and the boarding point may be up to a kilometre or more. If a person has significant physical disability, that may make moving around an airport quite difficult, so wheelchair assistance may be needed, and a travelling companion is nearly always necessary.

Once up at flying altitude, apart from the important question of toilet access in the airplane, two other problems need to be guarded against for a trip that is usually longer in time than either train or bus travel. The first is clearly the possibility of a deep vein thrombosis, which is more likely with sitting down for long periods, especially if there is any degree of weakness in one leg. Wearing compression stockings is an important way of preventing this, and a doctor may also prescribe blood-thinning medications in some circumstances.

The second problem is that the cabin air pressure in flight is about equivalent to being at the top of a mountain around 2500 metres high, with the related issues of feeling dried out and cramped from sitting for long periods. Unless the person flying also has quite severe lung disease, this is not usually a problem. Newer aircraft, in particular the Airbus A350 and the Boeing 787, run with higher cabin pressures (thus the mountain top is not as high) and more humidification in the air conditioning, and a person will generally feel more comfortable at the end of a long flight in one of these newer aircraft.

### To sum up

Wanting to get out and about soon after brain tumour treatment is normal and natural. If a person wishes to drive themselves around however, they must be carefully assessed by health care staff, who know their legal responsibilities to provide a detailed and impartial recommendation. This needs to be discussed with the person and their family, as the possible outcomes may range from the person not being able to drive at all, or driving with various limitations, or being able to drive without restrictions. In any case, careful ongoing follow-up is essential; as in any other chronic disease, the circumstances of a brain tumour might change in future.

Finally, travelling long distances by bus, train or airplane is surprisingly easy for brain tumour patients who are not severely physically disabled, especially with a family member or carer to help.

The benefit of seeing friends or family separated by long distances will usually make all the hassles of such travel well worthwhile. ■



Raise awareness of  
the challenges of brain  
tumours - plan an event for  
International Brain Tumour  
Awareness Week 2017  
(21 to 28 October)

# The Pediatric Brain Tumor Foundation: in business to put brain tumors out of business

Robin Boettcher, President and CEO

Pediatric Brain Tumor Foundation



THE brain tumor landscape has improved since the Pediatric Brain Tumor Foundation (PBTf) was established in 1991 in the United States. But hundreds of children are still dying each year, and thousands of others are dealing with long-term physical, intellectual and psychological disabilities and tumor recurrence.

Today, while we seek a cure, the PBTf is working to have a greater impact on the lives of families living with this disease. We're reaching them earlier in a child's diagnosis and providing support throughout their journey.

Our goal is to serve all families affected by a pediatric brain tumor in the United States – to be the “go to” organization for this community.

Before their passing in 2009 and 2012, founders Mike and Dianne Traynor acknowledged that the PBTf needed to change to grow. We needed to accelerate progress and do more for kids and their families.

We began that transformation four years ago, building partnerships and alliances to expand both the “cure” and “care” components of our mission.

We know we can't do this alone. As one leading doctor said to me when I shared our vision for growth: “This is the new PBTf.”

**Right:** Chase Jones, a Pediatric Brain Tumor Foundation scholarship recipient, founded the Vs. Cancer Foundation, which joined forces with the PBTf in 2016.



**Above:** The Pediatric Brain Tumor Foundation's new California chapter offers English- and Spanish-language brain tumor family camps and a bereavement camp.

## Collaboration for a Cure

With the hire of our first brain tumor research program professional in 2013, we began to strategically diversify our portfolio, with greater emphasis on collaboration and innovation.

Dr. Joanne Salcido, PBTf's first vice president of research and advocacy, reinvented our annual scientific meeting to make it more robust and engage the leading childhood brain tumor experts from

academia, health care and industry to help shape our future research program.

To fund the best available research and grow that investment, we've reached out to other pediatric brain tumor and childhood cancer nonprofits to partner in our quest for better treatments and ultimately a cure.

Many smaller nonprofits lack the resources and expertise to review and select the best research projects, so that's a value-add we offer to our partners. Last year, four other



nonprofits chose to invest in PBTF's research portfolio, including a clinical trials consortium, a biorepository and projects seeking discoveries into glioma and medulloblastoma.

### Communities of Care

On the "care" side, the PBTF is also collaborating and forming alliances to increase and broaden support programs for children and families.

Known primarily for its survivor college scholarship program, the PBTF has awarded scholarships to more than 1,400 survivors over the past 10+ years.

One of these scholarship recipients, Chase Jones, created Vs. Cancer, which engages with sports teams to fund research and family support at children's hospitals. Today, Vs. Cancer is part of the PBTF, and Chase serves on the PBTF Board of Directors.

Joining forces with Vs. Cancer in late 2016 was our third merger – all in our quest to expand our outreach to children, families and healthcare providers.

We combined two years ago with the Brain Tumor Foundation for Children (BTFC) in Atlanta, now the PBTF Georgia Chapter, and last fall, the We Can Pediatric Brain Tumor Network became our California Chapter.

Our new California Chapter served more than 400 individual family members in 2016 through brain tumor family camps – conducted in both English and Spanish – and a grief camp. Hundreds of others were served by trained parent mentors who met with them in the hospital and clinic setting.

When the BTFC in Atlanta joined us, we took on their signature support program, emergency financial assistance. In 2016 alone, the Butterfly Fund helped 450 families through 23 hospitals in 11 states, easing the financial burdens caused by a child's brain tumor diagnosis.

We're becoming thought leaders in family support because we understand the importance of the parent's voice in that programming.

For the first time, parents are helping us create programs and services that are needed most, such as our Starfolio toolkit for newly diagnosed families and educational forums where families can learn from medical experts and each other. We've been very fortunate to have partnered with several other nonprofits to fund those programs.



Above: Couture for Kids, hosted by the Pediatric Brain Tumor Foundation's California (left) and Georgia (right) chapters, gives childhood brain tumor survivors an opportunity to shine alongside celebrity and professional fashion models

### A Future of Thriving

The steps we've taken over the past four years have laid a strong foundation for the PBTF's future.

To serve people more effectively where they live, we need to be closer to the children and families who are affected. We now have boots on the ground across the country. In addition to our national headquarters in Asheville, North Carolina, staff members are working with families and volunteers in Atlanta, Los Angeles, Houston, Chicago and Philadelphia.

This will enable us to expand our emergency financial assistance program into new hospitals in 2017, as well as replicate

California's family camps and peer mentoring programs in other parts of the country.

Furthermore, we're seeing through the work of Chase and Vs. Cancer just exactly how one survivor's story can change the world.

We're passionate about helping survivors thrive. In addition to our college scholarship program, we're investing in programs that help adolescents and young adults cope with survivorship challenges.

The PBTF is working with a renewed sense of drive and urgency because the kids can't wait. We're in business to put this disease out of business. ■



Above: Walkers in the 2016 New Egypt, New Jersey "Walk to End Brain Tumors"

### Walk to End Brain Tumors

Bruce Blount of the Grey Ribbon Crusade in the United States advised that the 5th Annual Walk to End Brain Tumors in New Egypt, New Jersey took place in May 2016 and raised over USD \$16,000 for brain tumor research. A total of 60 miles was symbolically donated to the IBTA's Walk Around the World for Brain Tumours. ■



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# Canine companions contribute significantly to brain tumor research

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**Above:** Liz Pluhar, DVM, PhD, Diplomate American College of Veterinary Surgeons, Director of the Canine Brain Tumor Clinical Trials Program at the University of Minnesota with Dakota, a black Labrador treated with vaccine immunotherapy for an anaplastic meningioma. Photo: Sue Kirchoff, University of Minnesota College of Veterinary Medicine

Researchers with the University of Minnesota College of Veterinary Medicine and Medical School in the United States have been working together to find novel therapies for brain tumors. The team - consisting of Liz Pluhar, D.V.M. neurosurgeon, Matt Hunt, M.D. neurosurgeon, and Mike Olin, Ph.D. researcher - are striving to prolong the disease-free and overall survival times for patients with high-grade glioma primarily using immunotherapy strategies.

Historically, the development of novel cancer therapies has relied heavily on preclinical animal models, where brain tumors develop after tumor cells are injected into the brains of healthy mice or rats. However these induced models of brain cancer have many drawbacks. It has become evident that studies using young, typically female mice often fail to accurately represent the older, obese and heterogeneous human population that develops cancer, resulting in the fact that <10% of oncology drugs that work well in mice are ever approved for human use.

## Spontaneous cancers in dogs make them ideal for studying cancer biology

There is a growing body of evidence that treating pet dogs with naturally occurring cancer is a translational bridge between basic studies in mice and human clinical trials. This is fueled by the similarities between canine and human cancers. Current estimates are that two to four million dogs are diagnosed with cancer in the US each year, which means that the incidence of cancer in dogs (5300 cases/100,000 dogs per year) is much higher than that in humans (500 cases/100,000 people per year). Spontaneous cancers in dogs make them ideal for the study of cancer biology and the development of novel immunotherapies that benefit both canine and human patients to extend their lives and advance scientific knowledge about brain tumors.

Brain tumors also occur more frequently in dogs than humans, with astrocytoma/glioma accounting for 20-36% of primary brain tumors in dogs and 25% in humans. Other similarities between the



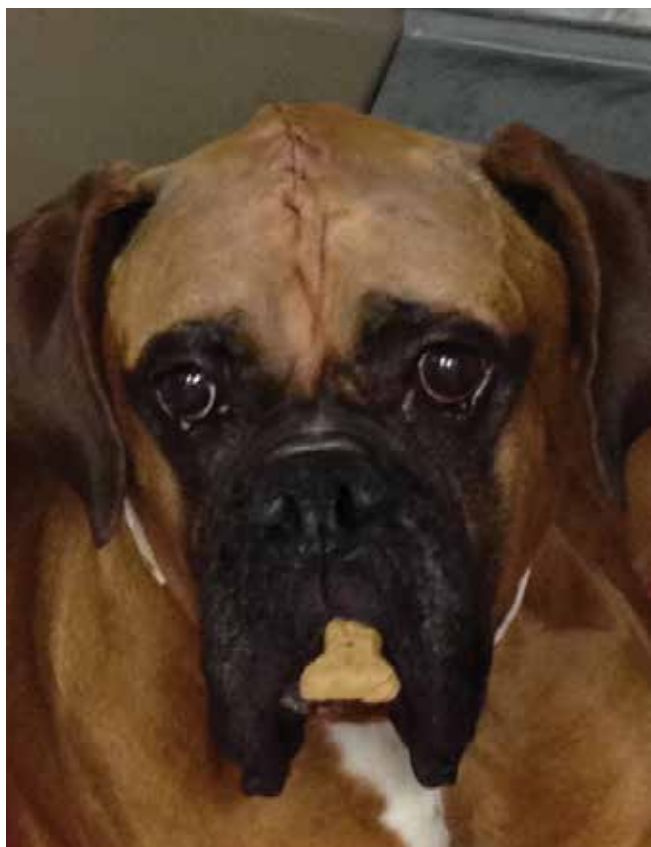
**Above:** Liz Pluhar, DVM neurosurgeon (left), and Matt Hunt, MD neurosurgeon (right), performing surgical resection in a Boston terrier, Marley, with a glioma. Marley is alive and disease-free more than 500 days after surgery and treatment with tumor lysate vaccines and novel checkpoint blockade inhibitor.



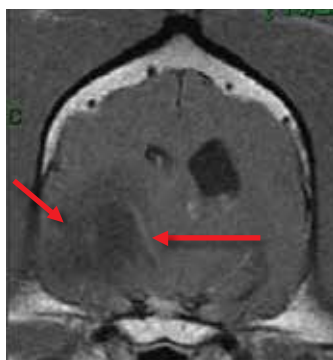
**Above centre:** Marley tolerating his Halloween costume.



**Above right:** John Huls, human GBM patient, receiving vaccine immunotherapy meets Piper, canine brain tumor patient, also being treated with tumor lysate vaccines after surgery.



**Above:** Brodie, a 7-year-old Boxer, enjoying a treat six hours after surgery to remove an anaplastic oligodendroglioma from the right temporal lobe of his brain.



**Left:** Brodie's MRI - T1W post-gadolinium image showing Brodie's large non-contrast enhancing tumor in the right temporal lobe (red arrows).

canine and human tumors further support testing novel therapeutics in our canine companions, such as neuropathologic and clinical abnormalities. The tumors arise most commonly in the fronto-temporal lobes with similar clinical symptoms such as seizures and changes in conscious and unconscious mental activity in both species. Interestingly, short-muzzled breeds such as Boxers, French and English bulldogs, and Boston terriers are at significantly increased risk of developing glioma, and account for the majority of the patients that Dr. Pluhar has treated.

Similar to that in humans, the prognosis for dogs with brain tumors in general is poor regardless of therapeutic intervention. However, little is known about canine glioma treatment outcomes because so few studies with a handful of dogs have been reported. The median survival time is counted in days for dogs that do not receive any treatment and is two to three months with palliation alone.

### Hope for dogs with brain tumors

The owners of most dogs will spend thousands of dollars for a tentative diagnosis of glioma based on an MRI, only to be given no definitive therapy and a hopeless prognosis. Many turn to the Internet to find help for their beloved pets and find the Canine Brain Tumor Clinical Trials Program initiated by Dr. Pluhar and the late John Ohlfest. They have offered hope through recruitment into clinical trials which are largely supported by external funding.

The problem with brain tumors is that they can hide from the immune system because the cancer cells typically don't have surface proteins that allow the immune system to recognize and kill them.

The premise of immunotherapy is to exploit the body's own immune system to recognize that the tumor is "foreign" material and to attack and kill any tumor cells. We have primarily used the patient's own tumor to make lysate vaccines that are injected into the skin to activate resident immune cells, called dendritic cells. This approach is similar to dendritic cell vaccines, but without the expensive and time consuming steps of removing immature cells, exposing them to tumor antigens outside the body, and then delivering them back to the patient. ➤

We think that surgery is an important part of the therapy to remove as much tumor as possible so as not to overwhelm the immune system. Vaccinating pet dogs with high-grade glioma after surgery increased median survival over that of palliative therapy from one to two months to seven to nine months. The dogs have an excellent quality of life with minimal adverse effects, which are significant advantages over radiation and chemotherapy.

### Promising results with novel treatment approaches

These earlier studies demonstrate the power of the canine model for the study of novel immunotherapy strategies. However, we continue to endeavor to improve our clinical results by adding checkpoint blockade inhibitors and/or gene therapy that is injected and, therefore, is active around the tumor resection bed.

The University of Minnesota researchers think that surgery followed by combining the two experimental agents in one study - a one-two punch of gene therapy followed by vaccine - may have a greater impact on the cancer. If this two-step process works, it could have significant importance for improving treatment for brain tumors in both animals and people. Preliminary data from a pilot study combining a canine-specific novel checkpoint blockade inhibitor with our vaccines after surgical debulking of the tumor is showing promising results with median survival times approaching a year.

### A dog named Batman has contributed to our knowledge of brain tumors

A serendipitous discovery from these studies was realized with our very first clinical trial patient, a ten-year-old shepherd-mix dog named Batman, diagnosed with a gemistocytic astrocytoma.

It turns out that our vaccine-based immunotherapy is very effective in dogs with low-grade glioma with median survival times over 855 days. Moreover, a few dogs with a tentative diagnosis of glioma were eventually diagnosed with anaplastic meningioma. These dogs also responded to the tumor lysate vaccines living the full extent of their lives without tumor recurrence, and led to a double-blinded placebo controlled clinical trial for meningioma. This trial that just concluded confirmed the findings of the dogs that were initially treated - the tumors do not recur for the life of the dog.

We now have an external sales organization to create and provide meningioma vaccines for dogs across the US, and we are in discussions to initiate clinical trials for people with meningioma, especially those that are high-grade, recurrent or inoperable, for whom there are a limited number of viable treatment alternatives.

Ultimately, it is our goal to continue to provide hope and safe, more effective treatments for dogs and people with any brain cancer. ■

Futher information: <https://www.vetmed.umn.edu/centers-programs/clinical-investigation-center/current-clinical-trials/canine-brain-tumor-clinical-trials-program/apply-brain-tumor-clinical-trials-program>



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

**LEARN MORE AT**  
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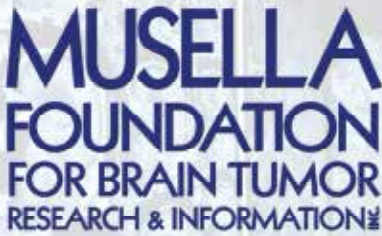
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- Online Support groups
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- Brain Tumor Virtual Trial
- Toll Free Patient Help Line: 1-888-295-4740

**Brain Tumor Research**

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

**Brain Tumor Activism**

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

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## FIGHTING AGAINST BRAIN TUMORS TOGETHER

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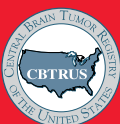
Join the National Brain Tumor Society and the global brain tumor community by helping us find better treatments, and ultimately a cure.

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National Brain Tumor Society

[www.braintumor.org](http://www.braintumor.org)




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# The little charity that could

Jennifer Egan, Secretary of the Kortney Rose Foundation Board of Trustees in the United States, describes how one mother's perseverance helped raise over US \$1.5m for pediatric brain cancer research.

WHAT do you do when your nine year-old daughter's life is tragically cut short from a rare brain tumor?

Kristen and Rich Gillette of Oceanport, New Jersey in the United States turned their grief into action. They established the Kortney Rose Foundation (KRF) in 2006 to preserve their daughter's memory while helping researchers try to find a cure for pediatric brain tumors, the number one cancer-related cause of death in children.

Kristen Gillette serves as the foundation's president. She has made it her life's work channeling Kortney's spirit and energy to raise money to advance research aimed at curing brain tumors through community-based fundraising. With a battle cry of "Help Get Brain Tumors Off Kids' Minds," she has enlisted an army of volunteers who help defray the administrative costs of multiple fundraisers. This allows the charity to commit 94 cents of every dollar raised directly to research.

KRF's signature fundraiser is "Kortney's Challenge," an annual two-mile family fun run/walk, which now draws over 600 participants. Cumulatively, Kortney's



Above: Kortney Gillette, the inspiration for the Kortney Rose Foundation

Challenge has raised over \$250,000 from 11 runs, and was one of the first fundraisers to contribute miles – now approaching 6,000 – to the International Brain Tumour Alliance's "Walk Around the World for Brain Tumors." Increased attendance and sponsorship from local businesses year-over-year at Kortney's

Challenge indicates that concern is spreading about the prevalence of the disease and the serious lack of funding.

At every opportunity to raise awareness, including Kortney's Challenge, Gillette stresses that only four percent of the National Institute of Health's (NIH) research budget is allocated to all forms of pediatric cancer research while children make up 20% of the population. "It's a crime, and it places the onus almost entirely on small, private foundations like ours to fund critical research for children with brain and spinal cord tumors," Gillette has stated.

Also on the awareness front, Gillette successfully lobbied state legislators to designate May as Brain Tumor Awareness Month in New Jersey beginning in 2009. Following Senator Edward M Kennedy's death from brain cancer, a similar bill was passed on the national level the following year. Gillette also engages her local area in decorating homes and storefronts for "Go Gray in May" and disseminates brain tumor facts of the day via social media.

Another priority of Gillette's has been to connect kids with the charity. The foundation has inspired teens in the area to run their own fundraisers at jewelry stores and organize school dances. The Kortney's Cash for a Cure is now collected at 25 schools and has raised over \$17,000 from area students this year.

To date, KRF has donated over a million dollars to Children's Hospital of Philadelphia (CHOP) and the Children's Brain Tumor and Tissue Consortium (CBTTC).

Gillette's dream of supporting collaborative research was realized with the establishment of the CBTTC, of which KRF was an original



Left: Kristen and Rich Gillette, Kortney's parents, started a not-for-profit as their little daughter's legacy





Above: One of the many energetic and enthusiastic teams taking part in the annual Kortney's Challenge. Walking mileage achieved is symbolically "donated" to the International Brain Tumour Alliance's "Walk Around the World for Brain Tumours".



Above: Ready, steady, hoola-hoop! Old and young alike enjoy the annual Kortney's Challenge

funding partner. While operated out of CHOP, it is a consortium of 15 global institutions.

CHOP's progress in brain tumor research in 2016 was pivotal. The CBTTTC operates the largest clinically-annotated brain tumor tissue database in the world and it is implementing systems like a pediatric cancer data cloud that could revolutionize the research landscape. Branded CAVATICA, CHOP created this data

cloud in conjunction with an adult cancer cloud developed by the National Institutes of Health (NIH). CAVATICA allows scientists around the world to view a full spectrum of specimens from adult and pediatric tumors enabling increased collaboration and broader implications for research discoveries. CHOP's use of collaborative science and data sharing through the CBTTTC and CAVATICA brought them to the attention

of the White House and Vice President Joe Biden's Cancer Moonshot Initiative, and they are now viewed as partners in this effort.

Especially meaningful to Gillette was a phone call she received last December from the CBTTTC Director Dr. Adam Resnick. Knowing that Kortney died from a diffuse intrinsic pontine glioma (DIPG), for which there is still no effective treatment or cure, Resnick informed Gillette that the pilot study done out of the CBTTTC would concentrate on DIPG and other high-grade gliomas. Even more exciting was the fact that the study is a multi-consortia effort working not just with the 15 CBTTTC member institutions, but also those of the Pacific Pediatric Neuro-Oncology Consortium (PNOC), which has 15 members. This is the largest research project ever done on this type of tumor, so accordingly KRF immediately made a multi-year commitment to fund the study and was the first foundation to do so.

"We are grateful to be involved in this pilot study as we believe it holds great promise for new discoveries," Gillette said. "What's even more thrilling is that this research will serve as a model for research on all pediatric cancers and beyond in the future." ➤





#### About the CBTTC\*

The Children's Brain Tumor Tissue Consortium (CBTTC) is a multi-institutional, collaborative research partnership dedicated to improving treatments and outcomes for children diagnosed with brain tumors. The nucleus of the CBTTC is a state-of-the-art biorepository and informatics portal, which allows researchers from all over the world to access high quality genomic and clinical tumor data. In October of 2016, the CBTTC was included as part of The White House Precision Medicine Initiative and is answering the Cancer Moonshot's call to de-silo data for diseases impacting children, including pediatric cancers, congenital disorders and rare diseases such as epilepsy and autism.

The CBTTC is comprised of 15

member institutions from around the world.\* It was established in 2013 and has since grown to become the largest, clinically-annotated database of pediatric genomic data in the world. Over 13,000 tumor tissue, blood, DNA, saliva and RNA samples have been added to the CBTTC bio-repository from more than 2,000 patient-subjects. Data collected by the CBTTC is available to the entire scientific and research community via CAVATICA, a cloud-based, open-source platform for collaboratively accessing, sharing and analyzing pediatric cancer data. This platform is scalable across existing genomic databases and allows researchers to share and analyze data in real time.

Additionally, researchers of CBTTC member institutions can request samples of tumor tissue for use in their own approved CBTTC research projects. All samples and data shared within the CBTTC are de-identified to ensure the privacy and protection of patient health information. Currently, the CBTTC has approved 16 scientific projects with two additional

projects under review. Data from approved project requests is typically available within one year following the receipt of specimens. Specimen data collected from scientific projects is added to the CBTTC database to aid in future discovery efforts.

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

\*Children's Hospital of Philadelphia (Operations Center), Ann & Robert H. Lurie Children's Hospital of Chicago, The Children's Hospital of Pittsburgh of UPMC, Seattle Children's Hospital, UCSF Benioff Children's Hospital, Meyer Children's Hospital (Florence, Italy), Children's National Health System, Weill Cornell Medicine Brain and Spine Center, Rutgers Robert Wood Johnson Medical School, Lucile Packard Children's Hospital Stanford, Hackensack University Medical Center, Children's Hospital of Orange County, Beijing Tiantan Hospital Neurosurgery Center (Beijing, China) and Genebank (Beijing Genomics Institute – Shenzhen, China) the University of California, Santa Cruz – Treehouse Child Cancer Initiative



#### Pacific Pediatric Neuro-Oncology Consortium

#### About PNOC\*

The Pacific Pediatric Neuro-Oncology Consortium (PNOC) provides access to innovative and more effective treatments to children diagnosed with brain tumors. PNOC comprises 15 participating institutions committed to precision medicine innovation through specific and targeted clinical strategies based on the genetic make-up of each brain tumor. PNOC's clinical trials and test therapies are aimed at interfering with specific cellular pathways or mutations, according to the unique characteristics of each patient's tumor. This targeted therapy reduces the need for generic patient therapy, requiring patients to receive only the treatment needed to treat their specific tumor type. The teams at each of the PNOC-

participating hospitals involve more than 100 specialists with expertise in different areas of pediatric brain tumor treatment – such as oncology, neurosurgery, and radiation therapy – who combine their expertise and collaborate to optimize care for each of PNOC's clinical trial patients. Nurses, social workers, and hospital staff with an in-depth understanding of the needs of families and children suffering from brain tumors are also members of the PNOC team. Additionally, scientists from each of the PNOC member institutions are actively engaged in laboratory research of pediatric tumor biology that continuously inform leading edge clinical trials.

PNOC is currently conducting numerous clinical trials across several different brain tumor types.

For more information about PNOC, visit [www.pnoc.us](http://www.pnoc.us)

\* PNOC member sites include The Pediatric Brain Tumor Center at Dana-Farber/Boston Children's Cancer and Blood Disorders Center, St. Louis Children's Hospital, Nationwide Children's Hospital, Ann & Robert H. Lurie Children's Hospital of Chicago, St. Jude Children's Research Hospital, Children's National Medical Center, Children's Hospital of Philadelphia, Seattle Children's Hospital, Doernbecher Children's Hospital Oregon Health & Science University (OHSU), University of Utah, Children's Hospital & Research Center Oakland, UCSF Benioff Children's Hospital, UCLA Mattel Children's Hospital, Children's Hospital Los Angeles and UCSD Rady Children's Hospital.

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## If you would like to donate to the IBTA...

We don't wish to receive any funds from organisations who support the "Walk Around the World for Brain Tumours" and the "International Brain Tumour Awareness Week" because it is crucial that these are directed to local, national and regional brain tumour support or research organisations in your own country.

However we do need some funding for our work and our publications.

So we welcome offers of funding from companies and philanthropic organisations and have a detailed sponsorship policy on our website that covers that subject. Enquiries should be directed to: [kathy@theibta.org](mailto:kathy@theibta.org)

If they wish to, individuals can also make donations directly to us via the on-line facility on our website [www.theibta.org](http://www.theibta.org) but please do not neglect your local or national brain tumour support groups.

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# Argentina: the Fifth Brain Tumor Awareness Day and First SNOLA Day

Dr Alejandra T Rabadán, MD PhD,

President of the Section of Neurooncology of the Argentine Society of Cancerology (SAC); Committee Chair of the Academic Council of Ethics in Medicine (CAEEM); Honorary President of the Section of Neurooncology, LatinAmerican Federation of Neurosurgical Societies (FLANC); Regional Director Committee Member of the Society for NeuroOncology LatinAmerica SNOLA; International Committee Chair of the AANS/CNS Section of Tumors.

The “Fifth Annual Brain Tumor Awareness Day,” and 1st SNOLA Day in Argentina, took place on 25 October 2016 in the building of the Argentine Medical Association AMA (Buenos Aires).

The Argentine Association of Neurosurgery AANC; the Section of Neurooncology of the LatinAmerican Federation of Neurosurgical Societies FLANC; the SNOLA (LatinAmerican Neuro-oncological Society); the National Academy of Medicine; and the Bioethics Institute of the Pontificia Argentine University also gave their academic support to the meeting.

The meeting started with the presentation of the analysis of the survey about the accessibility to the treatment of brain tumors in Argentina. This was the first observatory on brain tumors performed in our region. The complete report was published in the *Argentine Journal of Neurosurgery* 2016; 30 (4): 130-5. We expect this work will be the initial step in order to give academic support for quality management improvement.

Honourable guests from Brazil, the USA and Argentina gave lectures and actively participated in all sessions, talking about updates and future directions in brain metastases, low grade gliomas, high grade gliomas, and acoustic neuromas.

People from different disciplines such as neurosurgery, neuro-oncology, radiation therapies and palliative care attended the meeting. The number of participants in this meeting is increasing year by year.

A great effort was made to continue with this kind of meeting which, from the academic point of view, is high quality



**Above:** At the front door of the Argentine Medical Association Building (AMA) founded in 1891. Front row, left to right: Dr Veridiana Camargo (Sao Paulo); Dr Steven Kalkanis (USA); Dr Jose M Rotta (Sao Paulo, Brazil); Dr Alejandra T Rabadán (Argentina); Dr Ana M Martínez (Argentina). Back row, left to right: Dr JJ Mezzadri (Argentina); Dr Ricardo Ramina (Curitiba) and Dr Marcos Maldaun (Sao Paulo).

and open to the scientific community with free access. Through these initiatives, we hope to continue to foster education with the ultimate goal of providing an equitable neurosurgery practice for the people of Argentina. ■

**Right:** The Argentine Medical Association's Auditorium during Dr V Camargo's lecture.





# Walking towards a cure for brain tumours



BRAIN Tumour Foundation of Canada held 21 Brain Tumour Walk events in 2016 and thanks to the 7,342 participants, they donated 27,532 kilometres to the International Brain Tumour Alliance's Walk Around the World for Brain Tumours. That's more than halfway (59%) around the circumference of the Earth at the Equator.

Brain Tumour Foundation of Canada's biggest annual fundraiser is the Brain Tumour Walk program, previously called Spring Sprint. The program was renamed in 2016 to bring the brain tumour cause front and centre when referring to the program.

Brain Tumour Walk events take place in cities across Canada. In 2016, 21 Brain Tumour Walk events took place in nine provinces from Victoria, British Columbia to Paradise, Newfoundland. For the first time, a Canadian Territory also joined in, with the first annual Brain Tumour Walk held in Yellowknife, capital of Canada's Northwest Territories. Over seven thousand people participated, raising awareness of the brain tumour cause and much needed funds for Brain Tumour Foundation of Canada. An incredible CAD \$1.6 million was raised in 2016, which is directed to life-changing research as well as the programs, education and information that Brain Tumour Foundation of Canada provides.

At the Brain Tumour Walk events, brain tumour survivors are clearly recognizable in their distinctive blue t-shirts. While each event has its own unique touches, each event will honour brain tumour survivors, remember those who have walked before, and celebrate the hope that every gathering brings.

Each person joins a Brain Tumour Walk event for different reasons. For Lilli, a brain tumour survivor who joined the Toronto Brain Tumour Walk in 2016, it was to ensure that support and help is available to other people if they are diagnosed.



Above: The starting line up in Toronto, Ontario for the Brain Tumour Walk 2016.

Lilli said: "I didn't know there was support out there for people like me, and I really didn't think I needed it. But it turns out I did. We need to make this information easy to find, to make it readily available so that it's well-known and credible, and everyone can find it. That's my hope for the future."

The Brain Tumour Walk program is open for 2017 and we hope to raise even more funds and brain tumour awareness when



Above: Warming up prior to the London, Ontario Brain Tumour Walk 2016.



Above: A brain tumour survivor, recognizable by his blue shirt, walks to end brain tumours in Edmonton, Alberta in May 2016.

we return to all 21 cities again. London, Ontario this year will see the 24th Annual Brain Tumour Walk event. We are already looking forward to 2018 when the events will mark their quarter-century.

Thank you to those who have already joined the movement and to those who will join the movement to end brain tumours in 2017! ■



Above: Brain tumour survivors gather for a picture before the Brain Tumour Walk event in London, Ontario.

# Changing care needs for patients and caregivers throughout the brain tumor journey

Mary P. Lovely, PhD, RN, CNRN

San Francisco, California, United States

FACING a diagnosis of a brain tumor elicits shock and disbelief. So many decisions have to be made and changes occur rapidly. After years of experience and through qualitative research, it appears that specific phases of care emerge throughout the journey.(1)

These phases include:

- initial diagnosis
- post initial treatment phase which involves learning how to live with the brain tumor and
- declining stages which may lead to end of life.

Patient and family needs change during these phases.

## In the beginning...

The initial diagnosis phase is when patients and families are often faced with rapid decision-making. The brain tumor may need surgical removal or it may not be able to be removed surgically. Patients are offered standard treatments or other options such as clinical trials. Most people step out of their normal life patterns and focus on attacking the tumor. There are worries that a brain tumor may affect someone's thinking and change their inner being.

Optimally, the patient and family will locate specialized neuro-oncology care to obtain the best treatment available. Many excellent on-line resources bolster knowledge about the latest treatments.

Some hospitals and clinics have now employed "navigators" who can give guidance to the patient and family in the initial phase of a brain tumor diagnosis. This person is commonly a health care professional who will provide local and web-based educational brain tumor resources, facilitate discussion with health care teams,



Above: Mary Lovely

and identify financial or other barriers to treatment. Navigators are becoming more common because they can help smooth out a range of issues facing patients and their families when they start this journey.

In addition to treatment, health care professionals will identify symptoms that may be decreasing the patient's function and quality of life. Having baseline measures of these symptoms will enable health care professionals to track changes over time. Common symptoms of a brain tumor include:(2)

- fatigue
- drowsiness
- difficulty remembering
- disturbed sleep
- distress

Seizure control is also important. Managing these symptoms in the initial phase will help patients and families cope.

## Post-initial treatment phase

Patients and families have entered the

post-initial treatment phase when they have settled into the reality of a loved one having a brain tumor. It is a dynamic period. Patients may be placed on different types of treatments that may have side effects. They may experience decreased functioning in movement, vision, speech, pain or touch, or in cognitive status. Patients recognize that their lives have changed since prior to the diagnosis and they feel the loss of who they were before. Many people experience a change in roles and relationships. Roles may be reversed or assumed by the caregiver. Parenting dynamics may alter as the person with the brain tumor focuses on treatment, and the caregiver assumes more responsibilities. Children may undertake premature caregiver roles. Changes in intimacy between couples may arise.

Sometimes patients feel very dependent because they have lost their driver's license as the result of a seizure. Patients may lose the ability to spontaneously enter activities because of feeling sick, attending treatments or MRI appointments. Patients and families must carefully plan or sometimes abandon activities. Friends may become distant because of the fear of a brain tumor diagnosis.

## When the world seems very dark, light often emerges

Long term survivors have told us that a "new reality" usually emerges.(1) A patient and their family begin to acknowledge and accept that change has taken place. They begin to set new priorities based on current abilities and choices. Most people slow down and evaluate their life. Since slower processing and difficulty



layer of support when a person has serious symptoms (at any stage of his illness) or is moving toward the end of life. Palliative care specialists encourage and facilitate open discussions about decision-making, goals and desires. Ideally, patients and families are referred to specialist palliative care providers before major cognitive changes occur so patients and families can jointly discuss issues such as advanced directives. Specific symptoms are associated with end of life for brain tumor patients, and these can be mitigated with appropriate intervention. Health care providers work closely with patients and families to find peace at the end of life. Hospice is an excellent resource for end of life care.

In summary, patients and families experience phases of care after diagnosis of a brain tumor. Many aspects of life change as the result of this diagnosis, and people need guidance from a range of specialists and resources. Health care professionals, patients, families and others work together to find the best treatment and solutions to optimally live with the diagnosis of a brain tumor. ■

with multitasking may occur, patients and families change expectations about their work and family routines. They often decide to take one day at a time. Some people make healthier choices by eating a balanced diet and adding a regular exercise program.

The “new reality” of living with a brain tumor often means finding novel social settings and support since some old friends and supports may not understand the changes taking place. Family commonly remains the most consistent support. Health care professionals continue to accompany the patient and family throughout this journey. But patients and family may discover other outlets. Brain tumor support groups and family conferences are very good venues for meeting people tackling the same issues. A number of websites offer social support through discussion groups or patient-to-patient and caregiver-to-caregiver programs. Some people find it helpful to participate in spiritual activities through places of worship and like-minded communities. Meditation and yoga groups may be a peaceful way to feel more centered. Pets become loyal companions.

Caregivers face challenges throughout the journey and may experience unhealthy stress. They may have high levels of anxiety and depression.<sup>(3)</sup> Usually, their lives change dramatically while caring for their loved one. Caregivers often need outlets to care for themselves. Rest, routine exercise, healthy nutrition and socialization keeps many caregivers on track.

Intermittent symptom assessment is very helpful to identify changes. These evaluations are elements of a good survivorship plan. Patients may experience declining physical movement, excessive fatigue, slowing in activities, vision changes, nutrition and sleep disorders. The caregiver may be the most common person to identify changes. Health care professionals gladly help patients and families find possible therapies or solutions that aid overall functioning and maintain positive quality of life.

#### **Palliative and hospice care**

The declining stage for people with serious and/or life threatening brain tumors is where palliative and hospice care integrate. Palliative care is an extra

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**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.**



*brainstrust's superheroes don't fly. They walk.*



FOLLOW the Seagulls, a two-day 50-mile walk across the Isle of Wight in the United Kingdom, unites the amazing people who have been eager to take on a challenge that matches their scale of passion for brain tumour support.

The walk was hard. The terrain was tough. The weather was windy. But we did it! We walked 50 miles in two days, took over one million steps collectively and raised a whopping £20,000 to help people with a brain tumour feel less alone and afraid and more in control. And the group also symbolically donated to the IBTA's Walk Around the World for Brain Tumours an impressive total of 950 miles!

Paula is one of the superheroes who joined us for the walk. Her experience was unforgettable:

"The Follow the Seagulls 50 miles in two days walk for brainstrust was the biggest physical challenge I have ever undertaken, and ahead of it I was full of doubts. Would I finish it? Would I get lost? Would I be struggling, huffing and puffing and slowing everyone down? The nearer it got to the time of reckoning the more daunting it all seemed.

"My worries were completely unfounded. It was an amazing experience. Yes, my legs ached, especially with the steep hills, but every



time I started feeling sorry for myself, I considered the people I was doing it for. What's a stiff back and tired feet compared to living with a brain tumour? Nothing. Those people were, and continue to be, my inspiration.

"The route was varied and scenic, and the views across the island were breathtaking. My fellow walkers were a fantastic bunch of people. We all encouraged each other along the way.

"I'd recommend this walk to anyone, and I'll definitely be taking part again next year. Hope to see you there!"

Below: 50 miles, two days on foot. This amazing group of passionate people walked one million steps collectively and raised £20,000 to help people with a brain tumour.

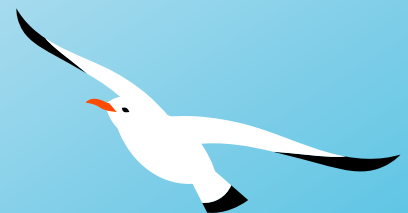
### Do something big for brain tumours

If you want to do something big, something truly memorable that will have a lasting impact for people with a brain tumour in the UK, then Follow the Seagulls 2018 is the event for you.

These self-supported walks will pit you against physical and mental challenges like no other. But you will come out the other side with a heroic sense of achievement. You will have overcome a major challenge and done something big that will help 60,000 people feel less alone, less afraid, and more in control in the face of a devastating brain tumour diagnosis. ■

### Ready for the challenge of Following the Seagulls?

Email [michael@brainstrust.org.uk](mailto:michael@brainstrust.org.uk) or call 01983 292405 (UK).





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Rainbows and Smiles is a community-based, registered Non-Profit Organisation, dedicated to providing support to children diagnosed with cancer, including paediatric brain tumours, and their families and caregivers.


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**Social Support** **Emotional Support** **Financial Support**



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## BRAIN TUMOUR IRELAND

Providing Support and Raising Awareness of Brain Tumours in Ireland

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<http://gfme.free.fr>

**GFME 15 years**

GFME, **Glioblastoma Foundation Michele Esnault**, established in **2001** is a French-based (Marseille), patient-oriented, support group involved in **brain tumors**. GFME translates and publishes in French **scientific publications** of Pubmed and **ASCO** on primary brain tumors. The association gives support, help, guidance on treatments and clinical trials for **adults and children** diagnosed with brain tumor. GFME works in partnership with ARTC, Brain Tumor Association For Research to rise funds. GFME is a website <http://gfme.free.fr> a quarterly magazine, a phone assistance (33) 04.91.64.55.86, and two mailing-lists ([gfme@yahoogroupes.fr](mailto:gfme@yahoogroupes.fr) and [astrocytome-gfme@yahoogroupes.fr](mailto:astrocytome-gfme@yahoogroupes.fr)). The group includes **650 patients**, care givers, **friends and family members** around the globe. For more details [gfme@free.fr](mailto:gfme@free.fr)



# SIMO...alla meta, SIMO...the goal



Above: A poster from the 2016

"Simo...alla meta" event

Below: Here's to Simone! Remembered with love...

2017 will mark the third year of the "SIMO... alla meta – Memorial Simone Luffarelli".

Simone Luffarelli passed away in Italy from a brain tumour in 2006 at the young age of 21. His brother, Marco Luffarelli, together with Simone's friend Valerio Rahim, are the founders of the not-for-profit organization ASD Chaos Primordiale which promotes and develops amateur sporting activities and organizes cultural activities.

In memory of Simone Luffarelli, a non-competitive run/walk is organized annually by ASD Chaos Primordiale and sponsorship money from it goes to the not-for-profit IRENE, the Regina Elena Hospital Association that supports patients with brain tumours and their families.

Marco said: "My brother, Simone, always faced his disease with a smile and so we gather together each year to remember his courage and warmth and to help other brain



Above: Marco Luffarelli (left - President and founder of ASD Chaos Primordiale) and friend Valerio Rahim (right - co-founder, vice president and coach at ASD Chaos Primordiale).





tumour patients at the Regina Elena Hospital to cope with this devastating diagnosis."

Apart from organizing this run/walk in memory of Simone, ASD Chaos Primordiale also trains in the parks in Rome and participates in many races.

The International Brain Tumour Alliance is proud to support this effort and congratulates Marco and his colleagues on their wonderful event in memory of Simone. ■

**Right:** Marco Luffarelli's young son, also named

Simone, enjoys participating in the walk/run

**Below:** Participants in the 2016 "SIMO...alla

meta" event in Rome warm up for their race/walk

**Below right:** The "SIMO...alla meta" event is in

memory of 21-year-old Simone Luffarelli




## From the IBTA Album...



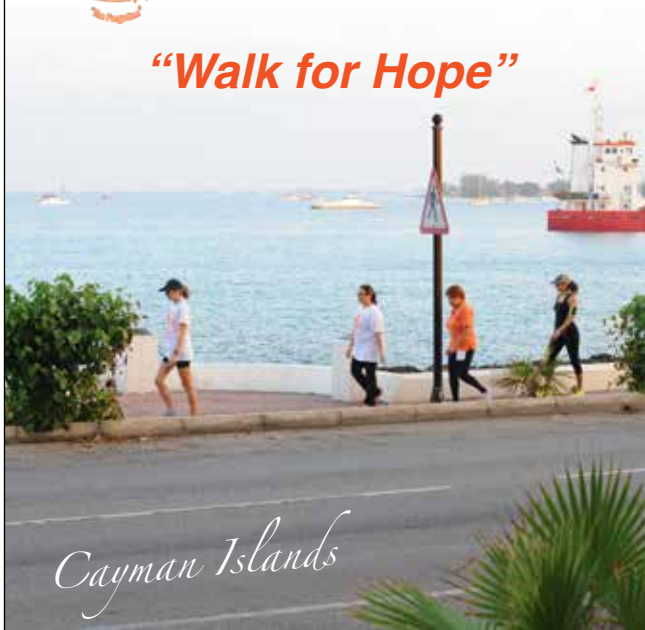
**Above:** The IBTA exhibits at the American Society of Clinical Oncology (ASCO) annual conference each year. We are in the ASCO-sponsored Patient Advocacy Booth in 2017 so we look forward to seeing you there. Pictured above are IBTA Director Gordon Oliver (left) with IBTA Senior Advisor Jean Arzbaeher (right).






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**SOUTHEASTERN BRAIN TUMOR FOUNDATION**  
[www.sbtf.org](http://www.sbtf.org)

# I have a rare opportunity to make myself useful to others on my own life-changing journey

Laureline Gatellier, PhD, MBA  
Tokyo, Japan

## My new life – “Let it go”

I had just turned 42 and, miles away from my Belgian family, was living in Tokyo, Japan with my Japanese husband and three-year-old daughter. We were very active in volunteering activities, supporting for five years in a row, people affected by the March 2011 tsunami which devastated northeast Japan.

My eyes opened to my new life on 9th February 2016, with an MRI checkup after several months with minor numbness (about one to two seconds per day) in my right hand and foot.

The tumor in my left temporal lobe was 8 x 5 x 4 cm. I thought my life expectancy was limited to a maximum of two weeks. It was not possible to move back home to Belgium. Urgent action had to be taken. I went through a first awake craniotomy that February (80% tumor reduction), followed by a second one in May (a total of 90% tumor reduction).

During each of the surgeries, my motor, language, memory and eye functions were checked carefully. My Japanese, English and



even French abilities were tested during the surgeries. After the post-operative checkups, I was officially diagnosed with a grade II astrocytoma.

These two surgeries were followed in July 2016 by CyberKnife radiotherapy and also chemotherapy during which I experienced hair loss and I learned that I had mild epilepsy, but with no visible effects.

My mother, my sister, my husband, my family and friends were always there to support me and give me positive energy.

## Networking helps!

While preparing me for radiation and chemotherapy treatments, my neurosurgeon used a word unknown to me: the ketogenic diet. He had read an article on clinical studies for this treatment in the International Brain Tumour Alliance magazine. He also told me that if I took on this new challenge, we would be pioneering in a new field. This was the time to take my life in my own hands.

The doctor's suggestion triggered me to read the article and contact the IBTA.

The IBTA introduced me to brain tumour patient advocates in Japan (my host country) and in Belgium (my home country) and, because I was interested in the ketogenic diet (KD), they named some of the people in the US and UK who are doing clinical studies on this approach.

With the support of my Japanese doctor (because this diet should be followed under medical and dietetic supervision), I embarked upon the “standard ketogenic diet”. At this stage, I have successfully integrated the ketogenic rules and the diet is now a part of my daily life. I can travel again and I even took part in a semi-marathon with very supportive friends.

## Living passionately

I feel I am doing something concrete from the patient's side.

Left: Discussing the future of patients and research.  
Left to right: Laureline, Melissa Lim (Brain Tumour Society Singapore) and Yuko Moue (Pediatric Brain Tumor Network, Japan)







Above: Post-diagnosis, with my husband and daughter

Brain cancer became a part of me; it is now time for me to find my way as a warrior in that new field, and contribute as much as I can to the wellbeing of other patients. This disease is also reshaping my daily career tasks. I work in the pharmaceutical field. I now have a clearer goal in my daily job with a better understanding of the feelings of patients than I ever had in the past.

There is fear. There is pain. There are new connections. There is belief. There is trust. There is the will to do more.

Concrete activities are shaping up ahead for me, now that I have started to realise deep inside of me that as I live with brain cancer, I can only be a warrior. As one of the first steps, in late 2016 I attended an



Above: After the first meeting with Yuko Moue (centre) from the Pediatric Brain Tumor Network and Hisato Tagawa (left) from the Japan Brain Tumor Alliance

international neuro-oncology conference to learn more about my disease.

Now, aiming for the future, my activities already include: active participation in the Japan Brain Tumor Alliance (JBTA), the Pediatric Brain Tumor Network of Japan (PBTN) and other groups of patients for whom my experience could be most useful. I started my work in the brain tumor patient advocacy community by sharing in February of last year recent neuro-oncology information I learned about at the Society for Neuro-Oncology (SNO) conference in the United States. Within the JBTA, we also agreed that I will be an active member in further patient meetings around Japan.

With PBTN, I plan to support their brain cancer kids summer camp, and entertain the children there with my volunteer friends from my life prior to my own brain tumour diagnosis.

I also plan to contribute to a better understanding and management of the ketogenic diet for patients in Japan. I have already started to interact with European and US specialists in this field as well as with Japanese clinicians.

Another dream of mine is to become an active supporter of open health data.

I feel that I have been given a rare opportunity to make myself useful to others and in particular, to those patients suffering from brain cancer.

When one starts realizing one is not immortal, life takes on another dimension and becomes all the more challenging and thrilling. ■



Above: Shortly after the first awake craniotomy, March 2016



Above: Finishing a half-marathon with friends, three months after starting radiotherapy and chemotherapy



Above: My mask being fixed prior to radiotherapy treatment, July 2016



# Building bridges, not walls

Dr Alexandra Diaz Alba

Guadalajara, México

I'M a neuro-oncologist in México, a country with a population of more than 127 million people. We are south of the United States and north of Guatemala. The official language in Mexico is Spanish but there are more than 68 native languages (such as Mayan, Uto-Aztecan, etc).

I studied in Guadalajara, the second biggest city in Mexico and then moved to Mexico City to study neurology at the National Institute of Neurology and Neurosurgery where I had the opportunity to study brain tumours under the tutelage of Dr. Alberto González. My final work while studying brain tumours was on the topic of the response of central nervous system lymphomas to corticosteroids.

Motivated by the lack of neuro-oncologists in Mexico I applied for, and was given, a scholarship for a fellowship at Hôpital Pitié-Salpêtrière in Paris with Professor Jean-Yves Delattre and Professor Khê Hoang-Xuan. The Pitié-Salpêtrière is the biggest reference hospital for brain tumours in France, with all the technology and medical help to learn how to diagnose and treat brain tumours.



Above: Dr Alexandra Diaz Alba from Mexico who is a neuro-oncologist

Things changed when I came back to Mexico to put in practice what I had learned.

Mexico is the second most populated country in Latin America and the eleventh in the world. Twenty-four European countries would fit in Mexico. In 1892, successful results of brain tumour surgery were

published, and in 1949 the first neurological institute (and still most important nowadays) was founded.

In Mexico there are three ways of getting medical assistance: (1) to buy private health insurance each year; (2) go to a public hospital with social insurance or (3) pay directly to the hospital/doctors. The minimum salary per day in Mexico is 80 pesos - about US \$4.00. A well known chemotherapy for brain tumour treatment - temozolomide - costs around \$9,401 pesos for five capsules at 100 mg each. This means that somebody without social or private insurance would have to work 117 days to buy half of the treatment he needs for one month.

Most of the health centres in Mexico are in big cities. Public hospitals are overcrowded and the waiting lists are long. There are 41 official oncology centres (infocancer.org.mx) but not all of them are used for treating patients with brain tumours. Since we are only a few neurologists with experience in neuro-oncology (less than ten for all of Mexico) it is difficult to create guidelines to treat Mexican patients, and the guidelines that are used in other countries aren't really feasible here most of the time.

Even when there is an economical way to buy treatment, chemotherapies largely used in most countries (like lomustine, which is the second line treatment for a very common malignant brain tumour called glioblastoma) are not available in Mexico and most of Latin America. So we have to figure out other ways to treat brain tumours.

Here in my country, there is a lack of protocols and investigations in neuroscience, particularly in brain tumours. However, day-by-day more people are becoming interested in learning and getting involved in the neuroscience field.



Left: Students from the ITESM (Instituto Mexicano de Estudios Superiores de Monterrey, campus Guadalajara)



Above: Salvador Ruiz Benavides, left, and his family

Although getting neuro-oncological advice and treatment in Mexico is difficult, people manage to travel to big cities to obtain it, as is the case with Salvador Ruiz Benavides, a 35-year-old man with a history of an ependymoma at age 21 and then a glioblastoma at age 35. Salvador has to take a bus to a bigger city and then a flight to Mexico City to get his chemotherapy. Fortunately, family and friends are always a very good support in the Mexican culture. "Chava", as his family call Salvador, is always accompanied by his mother Yolanda, one of his sisters and a family friend since it is difficult for him to walk by himself. He and his family are determined to continue the medical treatment no matter how far they have to travel.

There's a different picture when there's no social insurance. Family and friends who left to work in the United States play an essential role as economic supporters. Most have to stay abroad to work and send money for their loved ones' medical treatments. There are even associations of Mexicans in neighbouring countries who commit to and help family members of co-workers.

In Mexico, the relationship between doctors and patients or patient's families is very special: we treat in a very close manner and doctors are often the patient's confidante. Patients trust doctors as a child trusts his mother.

We Mexicans are committed to each other and we take care of ourselves and each other. Since we live in a time of political and economic crisis, the population has learned to fight for their rights and to speak up. Our youth are the future generation in Mexico. I am fortunate to teach neurology (as part

of the neuro-oncology program as well) at one of the highest-ranked universities in the country, where students are not only fully trained to be doctors but also to be good human beings. A lot of them decide to study abroad and then return to Mexico to implement what they have learned, to teach other physicians and to start creating the experience and know-how that Mexico has previously lacked.

Although times are changing in Latin America, we still need to organize ourselves

to take health care information and knowledge about brain tumours to remote areas of our country, to spread the idea that nowadays brain tumours can be treated, that survival is longer and quality of life is better in comparison to past years.

We need to tear down walls and build bridges, to trust ourselves as a country and as a part of something bigger.

I've been very lucky all my life. My passion for brain tumours doesn't come from a family member who was diagnosed with one or a story with a special patient. But instead my passion comes from the true need of the patients I saw during my residency program and the need of my colleagues to have someone with expertise in brain tumours.

I am very grateful to all those who helped me get through my training and to all those brain tumour families who struggle day by day. I am also grateful to the patients because they are the ones who give us hope and who motivate doctors to be better human beings. I am grateful to Kathy Oliver at the International Brain Tumour Alliance for inviting me to show how Mexico really is to all the world.

We do have a lot of needs but we also have a great culture which is worth knowing. ■

## From the IBTA Album...



Above: The IBTA exhibits at neuro-oncology and cancer congresses around the world. Here, IBTA Senior Advisors Chris Tse from New Zealand (left) and Sally Payne from Australia (centre) are pictured at the IBTA booth during the 2016 Asian Society of Neuro-Oncology (ASNO) and Cooperative Trials Group for Neuro-Oncology (COGNO) conference in Sydney, Australia in September 2016. Professor Roger Stupp is pictured (second from left) along with Brain Tumour Alliance Australia (BTAA) Chair Catherine Hindson (far right), and BTAA committee members Susan Pitt (second from right) and Philip Steel (third from right). Sally Payne is also a BTAA committee member.

# Running the Boston Marathon with Neurofibromatosis

Anne Shigley Noble

Meriden, New Hampshire, United States

*Neurofibromatosis (NF) is a genetic disorder that can cause deafness, blindness, bone deformities, learning disorders, and tumors to form on nerve tissues anywhere in the body. These tumors are usually benign, but could become malignant. There are three types: neurofibromatosis type 1 (NF1) (affecting one in 2,500 people), neurofibromatosis type 2 (NF2) (affecting one in 25,000 people), and schwannomatosis (affecting one in 40,000 people). (Source: Children's Tumor Foundation, [www.ctf.org](http://www.ctf.org))*

**M**y name is Anne. I enjoy running, doing artwork, and spending time with my family and friends. I try my best to cherish every day, because, figuratively speaking, I know that life can throw you an unexpected curveball and a lot of sour lemons (bad experiences), with which I've learned to make sweet lemonade (and try to turn the bad things into positive things).

I have been fortunate and defied the odds for most of my 29 years, and hope to be here to 80. I was diagnosed with neurofibromatosis type 2 (NF2) at age seven. Two years later, during the 1996 Olympic Games in my hometown of Atlanta, Georgia (US) I woke up one morning with my face contorted and I couldn't smile. An acoustic neuroma had paralyzed one side of my face, which doctors told my parents would be permanent. I was soon on an airplane to have my first craniotomy at House Ear Clinic in Los Angeles, California. I was nine years old and I thought I would die. Against the odds, I woke up after the neurosurgery grinning, although deaf in my right ear. After that, I had some issues in school but otherwise I had a pretty normal childhood.

Despite battling NF2, I became a high school runner. The first year I was always close to last, but by my second year I was running in the middle of the pack. While in high school I learned about the Boston Marathon. I began to dream of someday running it. But reading about the qualification times, I feared I would never be fast enough.



Above: College graduation day - Anne (right) and her proud Mom (left)

During my senior year in high school, my hearing in my one good ear began to decline from yet another acoustic neuroma tumor. Simultaneously, I had back pain from spinal tumors which threatened my ability to ever run – or even walk – again. I also suffered chronic stress fractures in my legs, probably from running off balance. I flew to Boston, Massachusetts to have surgery for the spinal cord tumors which came out without damage, then immediately flew to Los Angeles, California for another surgery on the brain tumor that deafened the left ear too and left me without balance.

I spent Christmas 2005 in a hospital room with a view of the famous “Hollywood” sign. Unfortunately, that surgery did not succeed in restoring my hearing.



Above: Anne and Steve starting married life together on their wedding day

Back home in Atlanta, I finished high school with a captionist beside me typing the lectures on a laptop. I then started Maryville College in Tennessee, again with help from a captionist beside me who typed the lectures on a laptop. In my college freshman year I ran my first marathon with my family and a group of classmates cheering me on, and then took medical leave to have the same tumor removed and to get my auditory brainstem implant (ABI). That summer, after activation of my ABI, I took a crash course in American Sign Language (ASL).

That fall I transferred to Rochester Institute of Technology/National Technical Institute for the Deaf (RIT/NTID). I spent summers in classes and several camp jobs throughout the United States. At RIT,





Above: Anne as a child

I met Steve and we got married after graduation. I continued running and, with Steve, added triathlons. I started a Master's Degree in early childhood special education but after our wedding, Steve had a job offer as a telecom engineer at Dartmouth College in New Hampshire so we moved there. Now we are in a house, in rural Meriden, New Hampshire, with a grand view of the mountains.

Normal hearing is analogue, which I can no longer do. However, ten implanted electrodes at my brainstem allow me to hear digitally, picking up environmental sounds. After years of dedicated therapy and practice, I've learned to interpret those sounds into understanding human speech and other sounds around me, so listening is like a giant puzzle missing a



Above: Anne working with Dr Catherine Clark, an audiologist at Rochester Institute of Technology/ National Technical Institute for the Deaf. Anne and Catherine worked together for about an hour each week for five years.

lot of pieces. In college another tumor had formed on my femoral nerve, which was removed in 2011, but left some atrophy and weakness in my right leg.

In 2013, I looked at the Boston Marathon website wistfully, knowing I would never qualify. That is when I discovered that there is a "mobility impaired" division for the Marathon. I asked friends and began to wonder if maybe I could get in. Some said they didn't think that I was disabled enough, but knowing how much my absent

vestibular nerves and damaged femoral nerve slowed me down, I decided to try it anyway. I needed to run a marathon in under six hours to qualify even in this division. I ran 5:18 at a marathon in November 2015 and immediately applied to the Boston Marathon.

At age 28, I fulfilled my dream of running the 2016 Boston Marathon - in the mobility impaired division - and also raised over \$5,000 for medical research supported by the Children's Tumor Foundation. I finished in a time of 5:10. ➤

Below: Anne runs the Boston Marathon in the disabled division with her guide



Grateful to God, my doctors and the entire community of support for medical research on neurofibromatosis, I dedicated my running in the Boston Marathon to the memory of less fortunate friends who have passed away. Several of my friends with NF have died in their twenties in just the past few years. I also ran to honor the many young heroes who are not able to run, and to support research.

The Boston Marathon experience was incredible, and I was amazed by the dedication of every athlete there, all with different stories but all with the same goal to reach the finish line. I ran three more marathons last year.

One afternoon in November 2016, I had four grand mal seizures but resumed running days later. I started a new drug trial in December 2016 in the hopes of shrinking or stabilizing a 3cm cranial benign meningioma. I also have eleven small tumors on my spinal cord and seven small cranial lesions which include optic neuromas behind both eyes.

It has been ten years since I became deaf and I am now adapting to new medication side effects. I ran my second Boston Marathon on 17 April 2017.

After completing the first three months of a new drug trial, I learned that my largest meningioma (benign) in my brain had grown 40% between autumn 2015 to autumn 2016, but since starting on the trial, it shrank by 8%, so I will continue to the second cycle in the trial. ■



Top: Hospital stay – one of many for Anne over the years

Above: Anne with her family (left to right: brother Ken, Mother, Dad and Anne) at a surprise birthday party for Anne's Mom who has survived a benign brain tumor for 28 years and now has another one in the visual processing part of her brain.

## Walking with the Swedish Brain Tumor Association



MARIELLA J Delgado of the Swedish Brain Tumor Association said: "We invited our members and their families to join a power walk of two kilometers in the beautiful green surroundings of the "Slottskogen" ("Castle Forest"), a 137 hectares park in central Gothenburg, Sweden. Here you can see elks, Gotland ponies, Gute sheep and other Nordic animals in the park zoo. Much of the park is given over to natural parkland with native trees such as linden, beech, maple and various species of oak.



Above: Within the beautiful Slottskogen, a large park in central Gothenburg, Sweden

"After finishing the walk we had a nice coffee break in one of the restaurants in the park and shared experiences and thoughts

about our lives as brain cancer warriors. It was very much appreciated and we plan to have more walks of this type.

"A total of 32 kilometres was walked by 16 participants and the mileage was symbolically donated to the IBTA's Walk Around the World for Brain Tumours." ■



Above: The Swedish Brain Tumor Association awareness badge. The line under the pin means "Your support gives hope".



# IL FONDO DI



per la ricerca sui tumori cerebrali

## Gio's Fund for research on brain tumors

As long as we continue to nourish research on the brain tumors of our children, we nourish hope.

Among projects currently supported

- ◆ dendritic cell immunotherapy of glioblastoma
- ◆ molecular stratification of high grade glioma in children
- ◆ morphine treatment which permits doxorubicin to cross the blood brain barrier in a rat model
- ◆ Engineered T cells for the treatment of glioblastoma

Il fondo di Gio – onlus <http://www.ilfondodigio.it/>

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Registered charitable trust, brainstrust is a registered charity in England and Wales (1114634), and Scotland (SC044642)



## The Danish Association for brain tumor patients and relatives



We seek to

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

HJERNETUMORFORENINGEN  
[hjernetumorforeningen.dk](http://hjernetumorforeningen.dk)

If you would like to join or support us, please contact:  
[formand@hjernetumorforeningen.dk](mailto:formand@hjernetumorforeningen.dk)  
+45 8191 9208

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PBTN Pediatric Brain Tumour Network JAPAN

We are the network of groups of the pediatric brain tumour patients and their families in Japan, who help each other to improve our quality of life through peer support and discussion on our web site, through organising a summer camp and by appealing to the government etc.  
For more information, see the website addresses below.

### Child Brain Tumor Parents Support Group

<http://www.pbtn.jp>

### "Child Brain Stem Glioma Network"

<http://glioma-net.com/page6>

### "cranio park"

(for craniopharyngioma patients and families)  
<http://cranio-park.fc2-rentalserver.com/>

### Pediatric Brain Tumour Support Group in Kinki prefecture

<http://miracle-brain.jimdo.com/>

### Japan Brain Tumour Alliance (JBTA)

<http://www.jbta.net/>





# In loving memory of Paddy

The Holton family in Ireland sets a new world record of the most siblings ploughing a field simultaneously - and raises money for brain tumour support and research at the same time!

## The Holton Family

Ireland

*Editor's note: This must be one of the most unusual activities that we have ever covered in 'Brain Tumour' magazine: fifteen siblings ploughing a field simultaneously to raise funds for brain tumour research and support. Not only did the Holton family in Ireland manage to do this but they set a new world record in the process!*

Paddy Holton was one of seventeen children born to Willie and Eilish Holton of Cloona, Enfield which is located in County Kildare in Ireland.

From an early age, Paddy had an interest in farm machinery, tractors, threshing machines and ploughs from growing up on the family farm.

Paddy began work with Roinn Poist agus Telegrafa (The Department of Posts and Telegraphs) in 1973 and retired from Eircom after 38 years' service in 2011. During this time Paddy made many lifelong friends.

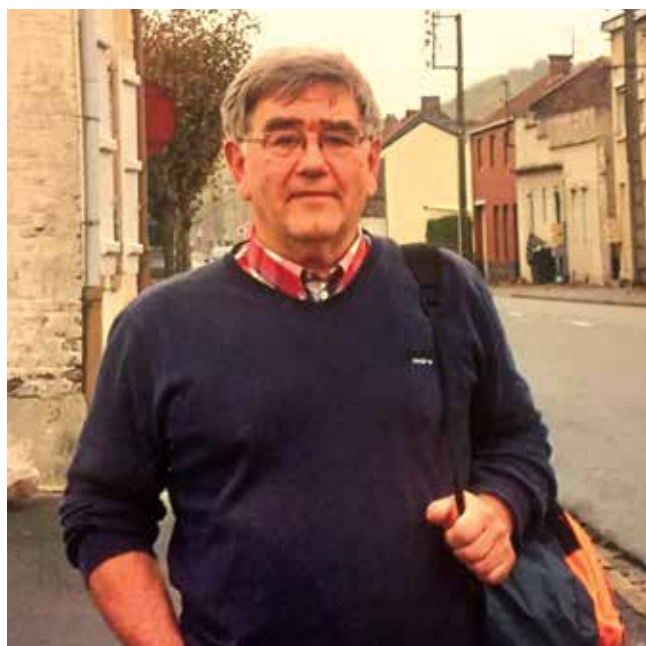
In 1985, Paddy married Bernie and they had two children Alice and Edward. Paddy always had time for a chat and loved to help others with board of management committees, the local cemetery committee and the Society of St. Vincent De Paul, the largest voluntary charitable organisation in Ireland, founded in 1844 and established to help people in need while seeking to achieve social justice and equality for all.

### Paddy and all things mechanical

A keen mechanic, Paddy was often fixing tractors, cars and other machines. Many Sundays involved outings to tractor runs, ploughing competitions and vintage shows both near and far. Paddy made many friends sharing stories at these events.

When Paddy was diagnosed with brain cancer in 2015, he was in the process of restoring a Ford 3600 Vintage tractor. In conjunction with the local Shamrock Car and Machinery Club, he was planning a challenge with his siblings to set a world record and raise funds for two organisations: Brain Tumour Ireland which supports brain cancer research and the Ross Nugent Foundation, in appreciation for the care he received in St. Clare's Ward at the Beaumont Hospital in Dublin.

The Ross Nugent Foundation raises funds for equipment in cancer units in Irish hospitals including Beaumont Hospital, Ireland's national centre for neurosurgery. Brain Tumour Ireland



Above: Paddy Holton, one of 17 siblings, inspired his brothers and sisters to set a new world record in his honour

is a national voluntary organisation providing information and support to brain tumour patients and their families and carers. It also promotes and funds medical research into brain tumours. Brain Tumour Ireland is funding a new brain tumour biobank in the Royal College of Surgeons in Ireland, which encourages research aimed at individualised treatments and increasing survival rates for brain tumour patients.

Unfortunately Paddy's plans to fundraise for these two organisations were not to be, as he passed away before he



Above: Paddy Holton's brothers and sisters line up – they set the world record for the most siblings ploughing simultaneously. No mean feat!



Above: The Holton family



Above: One of the Holton family tractors in action

could realise these plans. But his family decided to fulfil Paddy's wish on his behalf.

### Paddy's Wish

Sunday, 2nd October 2016 turned out to be a uniquely sunny October day in Kilglass Broadford. This meant that there were ideal conditions for the numerous Holton brothers and sisters to set the world record for the most siblings ploughing simultaneously!

It was all hands on deck from first light to set up the various marquees, stalls, wagons, stages, bouncy castle and all types of machinery and equipment for what would hopefully be a fun family occasion for the whole community.

Things were running smoothly, with people busy in every corner of the field until the last minute when the hired generator broke down. Indicative of the community spirit that would be evident throughout the day, a replacement generator materialised in a short time. After overcoming this little setback, everything fell into place.

The tractor run was first on the schedule of events with over forty tractors making their way from The Hamlet Court Hotel to the

event, passing Paddy's house en route. They arrived on time and took pride of place lining the field like a row of sentinels.

People began arriving in large numbers, with an air of excitement and anticipation beginning to build. The ladies were very busy making tea and coffee and serving a large variety of home-baked goods, which were also being added to as people arrived and donated their wares.

The sideshows and stalls, particularly Madame Cloona (the fortune teller), the traditional kitchen, face-painting, pot painting, balloons, dog show and bouncy castle along with stalls of local produce and crafts proved very popular. A world record for the longest queue for ice cream in October might also have been set on the day!

The excellent entertainment that was provided by Teresa Brayton Comhaltas (a group which promotes traditional Irish music, song and dance), Perfect Harmony, the Cully Brothers and Margaret Doherty added to the festival atmosphere and carried on throughout the day.

### The excitement mounts!

As 3.00 pm approached, the Holton siblings accompanied ➤





Above: You would have to go very far afield to find another family so talented at simultaneous ploughing as the Holton family in Ireland!

by Edward (Paddy's son) lined up their tractors and ploughs for the world record attempt. A blast of an air horn by Alice (Paddy's daughter) sent them on their way. The ploughing might not have been very straight but nonetheless the record was set, as confirmed by Billy Carey, Peace Commissioner (an honorary position in Ireland with special powers to take statutory declarations, witness signatures, and sign certificates and orders under various Acts) and solicitor James Wall. Certificates have been issued by the World Record Academy. Eilish (Paddy's mother) and Bernie (Paddy's wife) released two white doves to mark this momentous occasion and as a fitting way to remember Paddy, as his many siblings fulfilled his wish.

The Holton family were completely overwhelmed by the astonishing number of people who turned out to support them on the day. The spirit and generosity of the community, both leading up to the event, and on the day will remain with them for a long time. ■

Below: The official certificate confirming the Holton family's new world record of the most siblings ploughing simultaneously



Brain Tumour Ireland is extremely grateful to the Holton family, and their local community, for this wonderful fundraising event in Paddy's memory. For more information on Brain Tumour Ireland, see <http://braintumourireland.com>. For more information on the Ross Nugent Foundation, see <http://www.rossnugentfoundation.ie>



# Patient-reported outcome measures in neuro-oncological surgery

An opinion piece by Dr Prajwal Ghimire, MBBS, MRCSEd, MSc who is a medical graduate from Nepal and Master's graduate of King's College London currently working as a Clinical Fellow in the Department of Neurosurgery at King's College Hospital, London, UK



PATIENT-reported outcome measures (PROMs) are measures of outcome of treatment reported directly by patients.

They play an important role in addressing health-related quality of life (HRQoL) and patients' satisfaction with their outcomes. Neurosurgery is lagging behind in disease specific PROMs. So there is an emerging and urgent need for disease specific PROMs for neurosurgery - especially in neuro-oncology - to address quality of life issues, outcome satisfaction and patient safety.

PROMS can include post-operative pain and complications, health or functional status, wound-related issues, health-related quality of life status and outcome satisfaction. Neurosurgical operations play an important role in improving the quality of life of brain tumour patients but objective analysis and interpretation of such patient-related outcomes specifically from neurosurgical procedures are still lacking.

Studies have identified that the development of dedicated neurosurgery specific PROMs could be utilized in the clinical setting to properly address patient safety and compare outcomes of various neurosurgical procedures.

There are generic and non-specific PROMs currently in use in certain areas

of neurosurgery but not specifically for brain tumours therefore they don't address holistic neurosurgical quality of life issues. Examples of these would be: cervical spine outcomes questionnaire, hydrocephalus outcomes questionnaire, myelopathy disability index, etc. In neuro-oncology, although there have been developments of oncology PROMs and palliative care related PROMs, there is no PROM specific to surgical neuro-oncology. Such a PROM could potentially identify unmet needs of patients undergoing neurosurgery and offer individualized treatment options by bridging the existing gap between clinical practice and patients' perspectives and expectations. ■



## Rare Cancers:

- » More than 20% of cancers diagnosed in the EU\*
- » More than 4 million people in the EU affected\*
- » More than 500,000 new cases per year in the EU\*
- » Lower survival rates than for common cancers\*

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at [www.rarecancerseurope.org](http://www.rarecancerseurope.org).

Rare Cancers Europe is a multi-stakeholder partnership initiative addressing methodological and regulatory barriers in rare cancer care, the need for centres of expertise and European reference networks, barriers to patients' access to care, education of healthcare professionals and access to information on rare cancers. For more information, please visit [www.rarecancerseurope.org](http://www.rarecancerseurope.org).

\*Source: Gatta G., et al.: Rare cancers are not so rare: The rare cancer burden in Europe. Eur J Cancer. 2011 Nov;47(17):2493-511.



## PHILIPPINE BRAIN TUMOR ALLIANCE

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

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**WE ARE ON FACEBOOK:** Philippine Brain Tumor Alliance and "LIKE" us!

# I was a nurse for 40 years – but never understood the challenges of navigating a brain tumour until a family member was diagnosed with one

Catherine Hindson, Chair  
Brain Tumour Alliance Australia (BTAA)

I was a registered nurse and the manager of a suite of eight operating theatres in a private hospital when I retired in 2005. My husband Bill was 62 and had just been diagnosed with multiple myeloma, which is a cancer of the blood plasma. I was his full time carer for the past 12 years. He passed away this year in February. I have two daughters, Melanie and Renee, and three beautiful grandchildren.

I had always thought that when I retired I would want to volunteer for a worthy cause, but had no idea what it might be. Volunteering on the Brain Tumour Alliance Australia (BTAA) committee has been a welcome distraction from my late husband's health matters. I have made some wonderful friends through BTAA, for which I am grateful.

## My other reason for joining the brain tumour community

In 2010 my younger daughter Renee was diagnosed with anaplastic astrocytoma. She was 36 and had two small children. Despite having been a registered nurse all my adult life, I didn't know anything about brain tumours. I was an operating theatre nurse.

Renee was skiing when she had a bad fall and knocked herself unconscious. She thought nothing much of it at the time, but went to the emergency department four days later thinking she may have a fracture. They did a CT scan and discovered a golf ball-sized mass in her brain. After two months of scans and differential diagnoses, we finally got her to surgery in Sydney, about two-and-a-half hours' drive from home.

Renee's story was actually recorded on the television programme "RPA" which is a hospital reality TV show, filmed at the Royal



Above: Catherine and her husband Bill who sadly passed away in February 2017.

Prince Alfred Hospital in Sydney, Australia. The show has also aired internationally but usually under different names. It was pretty special and interesting to be part of the show. Not many people get the opportunity to see their child's craniotomy on TV. I suppose many would not want to, but given my background it seemed very natural.

When Renee was still in hospital recovering and waiting for the pathology results, she went on the Internet and

found Brain Tumour Alliance Australia. It was fortunate that she did. She had to travel interstate to have her surgery, so her neurosurgeon didn't know whether there was a support group near our home.

The week after she got out of hospital we were invited to Parliament House for the launch of a collaboration between BTAA and Beyond Blue (a depression support organisation). We joined the local BTAA group and found support and friendship.



**Above:** Several members of BTAA gather for a meeting (left to right): Catherine Hindson (Chair, BTAA), Mary Anne Rosier, Susan Pitt and Philip Steel.

I joined the BTAA committee in 2011 and became Treasurer in 2015. I am now the Chair. It is a really rewarding role. I have met so many wonderful people and I'm happy to be making a difference in peoples' lives.

### The right support is crucial on the brain tumour journey

Being diagnosed with a brain tumour is a life-altering event, no matter what type it is. My wish is that every single person diagnosed with a brain tumour – no matter whether it is so-called “benign” or malignant, and everything in between – can be connected with the information they need to make educated decisions on their care.

I want every patient diagnosed to have access to a support network. One of our great challenges is to educate the medical staff caring for newly diagnosed brain tumour patients to let them know that BTAA can be the first point of call for information, telephone support and to locate a support group in the patient's area. This is particularly important where patients are travelling away from home to get treatment. The medical staff can't be expected to know every support network around the country and this is where BTAA is a great place to start. Not everyone wants a support group, but everyone should at least have the opportunity to access one.

The other challenge I'm passionate about, in common with everyone in our BTAA team, is patients having access to dedicated brain tumour care coordinators. Even though I spent 40 years in nursing I never understood the challenges associated with navigating a brain tumour journey, until it happened to my family. I don't think anyone could. It's the ongoing care that is so important to patients and their carers, being able to ask medical questions and know how to access associated medical services available to them.

### The rewards and challenges of being a full-time carer

Being a carer is a demanding and crucial role when someone has a serious illness like a brain tumour or, in my late husband's case, multiple myeloma. During the dozen years that I was a full time carer to my husband Bill we went through many highs and lows. We managed to do two seven-month trips and two eight-week trips around Australia in our caravan. We had to plan ahead to make sure hospitals were ready to continue treatment when we arrived in bigger cities. We were very lucky with Bill's medical team. They were compassionate and encouraged and supported us to make those trips.

Family is the most important part of my life, so we spend as much time as we can



**Above:** The Brain Tumour Alliance Australia (BTAA) committee (left to right): Janet Micallef, Tricia Berman, Susan Pitt, Rigoula Roussakis, Catherine Hindson, Pam Hubner, Philip Steel, Alice Parsons and Sally Payne. Absent: Julia Robertson, Mark Dalliston and Mel Tempest.

together. We have made great memories of family holidays at the Great Barrier Reef, Fiji and I was lucky to accompany my daughter Renee and her children on the trip of their lifetime to Disneyland and Hawaii.

My daughters assisted me in providing home hospice care as my husband passed away. It was a wonderful experience and I am grateful to have been able to provide that for him. So I now have experience based on an understanding of the challenges of supporting a family member through their cancer journey right down to the last breath.

Being a full time carer didn't leave me much spare time, so I understand how important it is for carers to look after themselves. We need to discover the support networks available to us, including organisations, charities, families and friends, and we need to make the best use of them. Being a carer is very rewarding, but also very challenging. ■

BTAA has a support line run by people, including Catherine Hindson, who know what it's like to travel the brain tumour journey. BTAA can be contacted on Freecall 1800 857 221. See BTAA's free resources available for newly diagnosed adults and children on [www.btaa.org.au](http://www.btaa.org.au)

BTAA is run by a team of volunteers. To find out how to get involved and for more information about the people behind BTAA see: <http://www.btaa.org.au/page/10/our-people>



# Hjernesvulstforeningen - the Norwegian Brain Tumour Association



## Hjernesvulstforeningen

THE Norwegian Brain Tumour Association (NBTA) has been through a hectic period of growth and development since its founding in 2009. As a fairly young organization, NBTA is still developing its organization and areas of work.

The main work areas for the NBTA are:

- information about brain tumours for the general public as well as patients
- peer-to-peer learning and support
- influencing politicians, bureaucracy and other organizations

### Background to the NBTA's work and the Norwegian health and welfare system

Informational work is mainly directed through our membership magazine "Hjerne Det!" which can be viewed on our website at [www.hjernesvulst.no](http://www.hjernesvulst.no) and use of a variety of Facebook groups for communication as well as meetings and courses.

Peer-to-peer learning and support is our main service to the members. Many a brain tumour patient has felt relieved after talking to one of our peers. As one of our experienced peers once said: "The doctors may have the map, but we are the ones who have travelled the route and know it!" Our peers are in different kinds of services, varying from visiting patients, guiding patients and relatives about their rights and opportunities, to peer services at hospitals.

Norway has a good welfare system and good hospitals, but rules and regulations can be difficult to understand, especially for those who have cognitive dysfunctions due to a brain tumour. Some of our peers also



Above: Rolf J Ledal, Secretary General of the Norwegian Brain Tumour Association

offer a helping hand to patients and relatives by facilitating their understanding of how the systems work and guiding them through the intricate system of benefits and employee's rights. Sadly, many of those who suffer from brain tumours rapidly fall out of their jobs.

While social benefits compensate for some of the loss of income, many patients struggle with making ends meet. It's a goal of the NBTA to offer inspirational motivation to both employees and employers to make it possible to use the brain power that's available. Being able to work is the best way to have a good life, including for those with brain tumours. Part time or full time, the increased income and feeling of mastering life with a chronic disease plays a big part of life for many.

### The NBTA's policy work

During the last few years the NBTA has spent more time influencing our national politicians and health care system. The Norwegian health services are mainly public, with some private clinics offering different kinds of diagnostics and treatment. As a country with a small population and great distances, offering good hospital services can be difficult in some areas. It's a main area of interest



Above: Cathrine Aas Moen, Chair of the Norwegian Brain Tumour Association

for the NBTA to ensure that the process for diagnostics and treatment of brain tumours shall be of high quality and reliable for all – and not depend on where you live.

For more than a year we have had standardized and faster tracks for brain tumour patients. This was achieved through working together with the national directorate for health. Sadly, all non-malignant brain tumours are still not included in the program. Our brain health can be highly affected by non-malignant neoplasia also, and the NBTA is not satisfied with lesser services for this large group of patients. This is a matter about which we always voice our opinion when in contact with politicians and health care officials. We will not be satisfied before all brain tumour patients are given the best care and treatment that's available.

As a small organization in a small country, the NBTA is relying on cohesion and cooperation with other national and international brain tumour organizations. During the first annual Norwegian Brain Tumour Week in the beginning of May, we have an ambition to extend our cooperation and lay the foundations for a Nordic Brain Tumour Alliance. We know that we are stronger and better

together. The Nordic countries have more in common than that which separates them, and a stronger cooperation will be beneficial for patients and relatives.

### The NBTA Leadership

In April 2016 the NBTA decided to offer Rolf J Ledal, former Vice Chairman of the NBTA, the new position as Secretary General of the NBTA. The Secretary General has, as he cheerfully expresses it himself, "a thick skull". Rolf suffers from a bone tumour in the base of the skull, affecting some nerves and parts of the brain, so he has some knowledge about how life feels with less space for the brain!

Before he took the position as Secretary General, Rolf spent 30 years in the Royal Norwegian Navy, with a background in weapon systems as a technician and later as an officer within logistics and administration. His last commission was as a section commander in the Norwegian Defence Logistics Organization, Supplies Division, with the rank of Commander.

During his naval service, Rolf also spent 12 years as an ombudsman in Befaltes fellesorganisasjon, an organization for



**Above:** Meeting other patients and relatives gives knowledge and strength to managing to live with brain tumours

officers and non-commissioned officers in the Norwegian armed forces. His experiences from his personal life, his career and his organizational skills make him well-qualified for the position of Secretary General in the NBTA. Prior to this position, while acting as the Vice Chairman of the NBTA, Rolf was also a peer involved in the NBTA's peer-to-peer learning and support program.

The NBTA's Chair is Cathrine Aas Moen. Cathrine and Rolf are the two people from the NBTA who represent the organisation in most of the public and political settings.



Together they complement each other, with their different personalities and skills. The Chair of the NBTA is a non-paid position, and is responsible for the internal organizational and political work. The Secretary General is a paid position and is responsible for the daily business of the NBTA. ■

For further information about the Norwegian Brain Tumour Association, "Hjernesvulstforeningen", please visit [www.hjernesvulst.no](http://www.hjernesvulst.no)

## JACOB'S HOPE FOUNDATION

- ★ We are a new advocacy organisation for brain tumour patients and people with other cancers in Cameroon, Africa.
- ★ We educate survivors and caregivers on nutrition and quality of life.
- ★ We help establish advocacy groups in our country.
- ★ We provide information and raise awareness of the challenges of brain tumours and other cancers in our Cameroonian society by using colourful visuals so that people can absorb and remember information which will help them.
- ★ We have a Facebook page - search for Jacob's Hope Foundation

**You can phone us on 00237 677 344 981**  
**You can email us at: [ngong.irene@gmail.com](mailto:ngong.irene@gmail.com)**



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# Caroline's legacy - the Peace of Mind Foundation in Australia



PEACE of Mind Foundation, established December 2013, is a not-for-profit brain cancer charity based in Geelong, Australia. It was established to help improve the quality of life for brain cancer patients and their families through the provision of financial, emotional, social and practical support.

Clinton Matthews and Bec Picone (brother and sister) founded the organisation in honour of Clinton's late wife, Caroline Matthews, who passed away from brain cancer on the day of her thirty-second birthday. She was a new mother to their baby son Benjamin, when this disease claimed her life.

The story of Caroline's diagnosis is quite unusual and one we are forever grateful for, as it helped give her several more years with her family than she otherwise may have had if the tumour had remained undetected.

Caroline was employed as a registered nurse and had just begun working in an MRI department. On a quiet day the radiographer jokingly suggested that Caroline should have an MRI just so she knew what it felt like and could relate that to her patients. Upon conducting the MRI the radiographer instantly



**Above:** Participants at the February 2017 Family Retreat for Brain Cancer in Anglesea, Victoria, Australia  
Photo: Pam Hutchinson Photography

could see that there was a large abnormal mass in Caroline's brain and told her that she and her husband needed to come and have a meeting with the hospital as soon as possible.

The following day Clinton and Caroline met with doctors and were told that she had a frontal lobe malignant brain tumour (oligodendroglioma) the size of a tennis ball. This news would change our lives forever. Caroline lived for nearly five years after her diagnosis, but it was the extreme challenges

and lack of support encountered along the way that made Clinton and Bec so passionate about starting their own organisation.

In the three years since its formation, Peace of Mind Foundation has become one of the only support organisations in Australia that provides financial grants, in-home services, counselling and retreats specifically for brain tumour patients and families. Because the Foundation is self-funded and relies solely on public donations



**Right:** Peace of Mind Foundation Founder and Director Bec Picone takes a Lamborghini out for a spin at the family retreat. Photo: Louisa Jones Photography



and fundraising, the majority of our services are currently only available to our local patients and families living within our region. In the past few years we have had the privilege of providing direct assistance to over 150 families. The bulk of our referrals come through the hospitals or allied health agencies, and we also receive self-referrals from families who reach out to us for help.

Peace of Mind Foundation offers a very personalized approach to our clients and we often try to meet with the families in their home or discuss their supportive care needs over the phone to get a full understanding of their situation. Some of the services which we offer are small financial grants, in-home support (cleaning, garden maintenance, pet care), funded counselling, financial aid for transportation to appointments and mobility equipment hire.

We also help fund bucket list requests or send families away on holidays. We run the Geelong Brain Tumour Support Group which has a regular attendance of 20 to 30 people each month and is continuing to grow.

One of the main features of our organisation that we are incredibly proud of is that we host Australia's only brain cancer retreats. Thus far, each one has been super successful and enjoyed by all attendees. In February 2017 we hosted the first-ever Family Retreat for Brain Cancer. One hundred and twenty people (including volunteers) attended the retreat with families from all across Australia joining us for a weekend of fun, friendship and adventure.

Guests were spoiled for choice with the range of activities they could choose: jet skiing, four wheel driving, Harley cruises along the iconic Great Ocean Road, muscle car rides, chocolate factory tours, canoeing, bush horse riding and even rides in a bright yellow Lamborghini! Children enjoyed nonstop entertainment – music performers, jumping castles, farm animals, more fairy floss than was ever needed and even an appearance from Batman himself!

As with all of our retreats, we invited some incredible guest speakers to come along to empower and inspire our adult guests. We were privileged to have as our retreat guests Sean Purcell (The Unite Project) and Tim Diamond (Founder and General Manager of Cotton On Foundation). Both were fabulous and their stories really resonated with hope and determination ➤



Above: Simon Christie (4wdTV) has his heart melted by five-year old DIPG patient Alexia. Photo: Louisa Jones Photography



Above: Cruisin' at the retreat...Brain tumour patient Susan (centre) goes for a Harley cruise down Great Ocean Road with her 12-year-old son Max and her mum Laura. Photo: Louisa Jones Photography

for the patients and families who attended. We are looking forward to hosting our family retreat annually and to also expanding it to interstate locations in the near future.

In October, Peace of Mind will be hosting our 2nd Women's Retreat for Brain Cancer from the 13th to 15th October 2017 in Victoria. This is a weekend specifically for female brain tumour patients and/or carers and it's all about pampering, friendship and indulgence. A not-to-be missed weekend for every woman who has been affected by a brain tumour diagnosis.

Going forward, Peace of Mind aims to continue to expand our reach and, with enough funding, aims to be one of the leading brain cancer organisations in Australia for supportive care. It is our hope that one day we will be able to offer a majority of our support services to brain tumour-affected families all across Australia. ■

For more information about Peace of Mind Foundation or to find out how you can get involved please email us on [info@peaceofmindfoundation.org.au](mailto:info@peaceofmindfoundation.org.au) or visit [www.peaceofmindfoundation.org.au](http://www.peaceofmindfoundation.org.au).

## Astro Brain Tumour Fund Annual Walk

**ELEVENTH ANNUAL Norfolk Family Walk**  
at **Holkham Hall**  
for **BRAIN TUMOUR RESEARCH & SUPPORT**

**SUNDAY 15th OCTOBER 2017 10am-4pm**

Adults : £5 Children : FREE  
Car Parking : £3.00/car can be redeemed at the shop  
The walks are: 1, 3, 5, or 10 miles.  
The one mile walk for children has games along the way.  
Prams, trikes, wheelchairs and animals on leads are welcome.

**Brain tumours now account for more deaths among children and those under 40 than any other cancer.**  
Join others and **raise sponsorship** for your chosen brain tumour or cancer charity and **help us all find a cure** for this devastating disease.

The 2017 "World Walk" for Brain Tumours is a project of the International Brain Tumour Alliance (IBTA) and is in its eleventh year. We hope to achieve enough mileage world-wide to encircle the Earth at the Equator many times. The "World Walk" symbolically unites all those around the globe whose lives have been touched by a brain tumour.

Go to [www.astrofund.org.uk](http://www.astrofund.org.uk) to download a sponsorship form and for a link to create a justgiving page or contact via email: [treasurer@astrofund.org.uk](mailto:treasurer@astrofund.org.uk) or telephone: 01485 525279

Organised by the Norfolk Branch of Astro Brain Tumour Fund, charity no. 1123561

HOLKHAM IBTA astro brain tumour fund ABERNETHY FUND

THE Astro Brain Tumour Fund held its Tenth Annual Norfolk Family Walk at the beautiful Holkham Hall (UK) stately home on Sunday, 9 October 2016.

Despite the odd shower, everything went well.

Over 325 adults plus 93 children walked a total of 1,645 miles with over 60 dogs participating too!

Holkham Hall is a wonderful place to walk with roaming deer, amazing scenery, a large lake and wildlife all around. There is always a great, friendly atmosphere. See left for details of the 2017 Holkham Hall Walk. ■



## From the IBTA Album...



**Above:** The IBTA is an active member of the EURACAN European Reference Network (ERN) for rare cancers. IBTA Chair Kathy Oliver serves on EURACAN as one of the Rare Diseases Europe (EURORDIS) "e-PAGs" (European Patient Advocacy Group representatives). ERNs provide a unique opportunity for clinicians, allied health care professionals, researchers and patient advocates to work cross-border in European health care to tackle the specific challenges of rare diseases. The goals of EURACAN are to create networks of centres of expertise and to share and coordinate care across the EU to improve access to diagnosis and treatment and thereby improve outcomes for patients with rare cancers. Sitting under the umbrella of EURACAN there is a domain for brain and central nervous system tumours in which Kathy Oliver is also involved. Pictured above are some of the members of the EURACAN ERN which is led by Professor Jean-Yves Blay from Lyon, France (front row, fourth from right).



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Brain cancer kills more children than any other disease.

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SWEDISH  
**BRAINTUMOR ASSOCIATION** 

**We support** patients with primary brain tumors and every one who can relate to this group.

**Our work is carried out through:**

- Meetings and events
- Advocating

For more information:  
**Website:** [hjarntumorforeningen.se](http://hjarntumorforeningen.se)  
**Mail:** [info@hjarntumorforeningen.se](mailto:info@hjarntumorforeningen.se)

**You can also find us on**  
Facebook: [facebook.com/hjarntumorforeningen](https://facebook.com/hjarntumorforeningen)

Registered charity number 1153487 (England and Wales) SC046840 (Scotland)

**Brain tumours kill more children and adults under the age of 40 in the UK than any other cancer**


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

**THIS IS UNACCEPTABLE!**

**We are striving to fund a network of seven dedicated research centres whilst challenging the UK Government and larger cancer charities to invest more in brain tumour research.**


In collaboration with our Member Charities and other partners, we now have an influential role within the UK Government's new Task and Finish Working Group; a game-changing initiative that aims to address the UK's historic underfunding for brain tumour research.

**Together we will find a cure**



**Brain Tumour Research**

[www.braintumourresearch.org](http://www.braintumourresearch.org)  
Tel: +44 (0)1908 867200

 **BRAIN TUMOUR SOCIETY (SINGAPORE)**

**Bringing together a community of brain tumour patients, caregivers and medical professionals. BTSS is working to:**

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

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



# The PPR Foundation: brainstorming together for brain tumour awareness

Pamela Roberts, Founder

PPR Foundation, Harrogate, United Kingdom



## *Once upon a time*

in the city of Liverpool, United Kingdom, two children - a boy aged 12 and a girl aged 11 - met at Sunday school and became childhood sweethearts. From then on, their lives became one.

Their teenage years were fun and exciting. It was the era of the Mersey Sound, the Beatles, the Cavern Club, coffee bars, the mini skirt and so much more. They married at a very young age and had two very special children. They were soul mates, best friends and planned to live happily ever after. Well, that's what happens in fairy tales, isn't it? That is, until the day the fairy tale became a nightmare and they faced the biggest horror of their lives.

These two people were my husband Peter and I. Our idyllic life changed dramatically the day we were told Peter had a malignant brain tumour. This awful, chilling news was delivered to us on Peter's 56th birthday. We both knew from that moment on we were facing a cruel ticking time bomb and things were never going to be the same again. We still had so much to do, so much to see - we had so many unfinished dreams. In fact, we suddenly realised we'd barely started. We thought that, because Peter had retired at age 55, it was our time to do all the things that we wanted to do; we had so many plans.

We spent the next 12 months on fast-forward and we packed ten years into that time, treasuring moments when we could enjoy all life has to offer but, of course, with

Peter simultaneously enduring radiotherapy and various chemotherapy treatments. Our feet barely touched the ground and we were almost challenging death to catch up with us.

But it did.

I was then determined to raise awareness about brain tumours and also raise £1million for research. My idea was to ask one million people for £1 each and that would enable us to reach our target. The PPR Foundation began at my kitchen table with a £1 coin from a stranger.

No one has the ability to change the past, but we can certainly influence the future. It is now seven years later and the PPR Foundation is funding vital brain tumour research in Leeds under the leadership of Professor Susan Short. Dr Anke Brüning-Richardson is a senior research fellow and part of the same group at the Leeds Institute of Cancer and Pathology. Her research focuses on the development of novel drugs which stop brain tumour cells from spreading into healthy parts of the brain. The PPR Foundation funding not only covers Anke's post but also that of a much needed research

nurse, who consents brain tumour patients to allow use of their tissue for research, as well as a research technician who processes and looks after the samples. The team also recently welcomed a PPR Foundation-funded PhD student, Sophie Taylor.

Prior to Anke's recent post she held various positions in cancer research at Leeds University, which introduced her to the concept of public engagement involving laboratory tours for fundraisers, cancer patients and interested members of the public. When she started this outreach work she realised how much she enjoyed the interaction with people of various backgrounds and the opportunity to relay information about the research she does in layman's terms. Anke feels inspired by the drive and dedication of the PPR Foundation to push brain tumour research forward, and wanted to support this by doing public engagement-related activities to raise awareness about brain tumours, the work of the PPR Foundation and the research carried out at Leeds University.

Professor Short said: "Anke's extended role in the lab and relationship with PPR



Above: Dr Anke Brüning-Richardson (left) and her 11-year-old daughter Freya (right) with Pamela Roberts (centre, PPR Foundation). Anke and Freya developed "Brian the Brain" (see next page) to help raise awareness of the challenges of brain tumours.



**Above:** Kathy Oliver (left, Chair, International Brain Tumour Alliance), Pamela Roberts (centre, PPR Foundation) and Dr Anke Brüning-Richardson (right, University of Leeds).

highlights the value of public engagement to raise awareness of the dreadful impact of brain tumours and the urgent need for more research."

When the University of Leeds introduced a new scheme to apply for funding for public engagement activities Anke devised some novel educational and awareness-raising ideas together with her 11-year-old daughter Freya. Together they decided to create a soft quilted brain with detachable brain tumour and other associated toys such as a scalpel, x-ray beam and pill to symbolise the three treatment option for brain tumour patients. They involved a textile artist, Janice Garratt, to create these props.

"Brian the Brain" was conceived and completed in 2016 with funding obtained from one of the Leeds University public engagement awards. "Brian the Brain" has been to various science fairs and public engagement activities and certainly draws attention. Children are



**Above:** Pamela Roberts with Brian the Brain



**Above:** At the 2016 British Neuro-Oncology Society (BNOS) conference in Leeds, UK: Pamela Roberts (left), Founder, PPR Foundation, with Dr Susan Short (right), Professor of Clinical Oncology and Neuro-Oncology at Leeds Institute of Cancer and Pathology. The PPR Foundation supports Professor Short's work at the Translational Neuro-Oncology Group in Leeds.

fascinated by the quilted organ and come for a cuddle, which also instills curiosity in their parents. This allows Anke and Sophie to interact with young and old alike. They have had some very interesting conversations and a lot of interest in brain tumours and the work the PPR Foundation and the researchers at Leeds do.

Anke said: "Since starting on my research project I have learned a lot about brain tumours and their dire prospects. Working closely with Pam and the PPR Foundation I was appalled by the minimal exposure of brain tumours in the public especially in view of the fact that these cancers are the ones with the most abysmal outcomes in terms of life lost due to the disease. In addition, brain tumours constitute the cancers that especially affect the young, children and younger adults. We hear a lot about breast and prostate cancer but there is no mention of brain tumours. I felt that I needed to do my bit to address this lack of awareness." ■

For further information contact: the PPR Foundation, The Old Stables, Ripley, Harrogate, North Yorkshire HG3 3AX, United Kingdom. Our website is [www.thepprfoundation.com](http://www.thepprfoundation.com) and our telephone numbers are +44 (0)1423 771957 or +44 (0) 7785 368814. Registered Charity Number 1094805

## A patchwork public engagement activity: we need you!

DR Anke Brüning-Richardson is a senior research fellow and part of the group at the Leeds (UK) Institute of Cancer and Pathology. She is involved in research on the development of novel drugs, which stop brain tumour cells from spreading into healthy parts of the brain.

Anke is asking brain tumour patients, relatives, clinicians, researchers, people interested in science, young and old, to send her a textile-based piece of material (20 cm x 20 cm) which depicts the maker's associations with feelings of/ reflections on brain tumours.

This fabric can be knitted, stitched or glued but should be sturdy enough to be incorporated into a hanging quilt. You may want to highlight on your fabric, for example, the importance of brain tumour awareness or the hope that improving research into brain tumours brings.

Everyone who donates a piece of fabric will receive an official thank-you letter with a photograph of the completed quilt. The quilt will be used for awareness-raising at public science fairs, scientific meetings and other public engagement activities. We also hope to feature this initiative in local newspapers and through Leeds University and IBTA associated media. When sending in your fabric square, please include your home address. Please note that your fabric square cannot be returned to you.

The deadline for submission of your piece of fabric is 1 October 2017.

You can send your fabric square to Dr Anke Brüning-Richardson, Leeds Institute of Cancer and Pathology, Level 5, Wellcome Trust Brenner Building, Leeds University St James's Hospital Site, Leeds LS9 7TF, United Kingdom. Please email Anke if you have any questions or need further information: [bgyar@leeds.ac.uk](mailto:bgyar@leeds.ac.uk) ■

# Meet Sean Leong, the new CEO of Cure Brain Cancer Foundation in Australia



**Cure Brain  
Cancer  
FOUNDATION**

In December 2016, I was appointed Chief Executive Officer at Cure Brain Cancer Foundation in Australia. Our mission is to increase brain cancer survival from 20% to 50% by 2023. To this end, we currently fund 24 research projects, with more than 200 collaborators, across four continents.

My first few months at Cure Brain Cancer Foundation have truly been humbling as I learn more about the brain cancer journey and the substantial challenges facing people with this devastating disease. I've been helped through my first couple of months by a very supportive Board, who give up so much of their spare time to take on the responsibilities of shepherding Cure Brain Cancer Foundation. The staff at the Foundation have also made my transition as smooth as possible, and they continue to amaze me with their passion and commitment to the cause, as well as delivering some outstanding results.

## A corporate background

I come from a corporate background, formerly having worked for Westpac Banking Corporation where I was the Head of Trading and Risk Operations (COO), Group Treasury. But I have worked closely with not-for-profit organisations over the past five years so I understand the nuances of the sector. I've worked previously in the world of indigenous aged care (mentoring



Above: Sean Leong

an aged care facility), drug rehabilitation (helping to build a medical database to measure social outcomes for an impact bond application) and social enterprise.

In my time working in financial services I've experienced growth, volatility and uncertainty. The years I've spent refining my skills in previous roles have led me to a point in my life where I want to apply these skills and do something that has real purpose. So I'm very excited about this next chapter.

## Challenges ahead...

The first challenge that all not-for-profit organisations face is funding. Not all funding can come from our community, and it's time for the percentage that brain cancer receives from the Federal Government to increase. We then need to show that we are investing our supporters' money into projects that are demonstrating real impact.

But our mission will only succeed if we are able to accelerate research so patients can access promising treatments through clinical trials, and once they show results, there must be equitable access through our reimbursement system. This process doesn't happen quickly enough in Australia.

Another challenge that strikes me is the lack of clinical options for people with brain cancer. The current standard of care does not work well enough for the majority of brain cancer patients and, clinical trials aside, there are no other options, an issue we must address urgently.

Additionally, brain cancer awareness suffers from a paucity of patient advocates, unlike higher survival cancers. As we move closer to meeting our mission it will begin to be easier for us to increase awareness, which in turn will help us achieve desired advocacy outcomes.

## On my wish list ...

So, the first three items on my wish list for brain cancer patients, are:

1. Increased treatment options and removing the feeling of hopelessness that people living with brain cancer often have.
2. Change to the current system which too often slows (and restricts) patient access to the most promising treatments.
3. A 50 percent five-year survival.

I've derived a lot of job satisfaction from even the first few months of my time at Cure Brain Cancer Foundation, knowing that when I'm working long hours, the work that we are doing here matters and makes a genuine difference. The sincere gratitude and passion of the members of our community has also been very inspiring. ■

**The 2017  
International  
Brain Tumour  
Awareness Week  
is from 21 October  
to 28 October.**





# ARTC

Brain Tumors Research  
Association

## To support neuro-oncological research

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

## To act specifically

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

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

Association pour la Recherche sur les Tumeurs Cérébrales  
Groupe Hospitalier Pitié Salpêtrière  
Fédération de Neurologie – Mazarin  
47, Boulevard de l'Hôpital 75013 PARIS

**www.artc.asso.fr**

**Today 30  
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a brain tumour  
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# The IBTA and the European Federation of Neurological Associations

*The European Federation of Neurological Associations [EFNA] is an umbrella organisation for neurology patient groups across Europe. The International Brain Tumour Alliance is a member of EFNA and IBTA advisor Jenny Baker also represents the IBTA on EFNA's Trustee Board. Member organisations represent a wide range of neurological conditions apart from brain tumours such as epilepsy, stroke, motor neurone disease, Huntington's and Parkinson's diseases, multiple sclerosis, and others. EFNA's strapline 'Empowering Patient Neurology Groups' encapsulates its goals. EFNA's purpose is to add capacity – by supporting effective advocacy in members' own disease areas.*

*IBTA Senior Advisor Jenny Baker said: "As a new EFNA Board member representing the IBTA I am impressed by the difference EFNA is making for neurology advocates and look forward to help build on these achievements."*

EFNA's work is planned around four goals:

- advocacy
- awareness
- empowerment and
- engagement

This article explains what EFNA is doing in these areas and what this means for the IBTA.

## ADVOCACY

EFNA, with Pain Alliance Europe, coordinates the Member of the European Parliament (MEP) Interest Group on Brain, Mind and Pain Disorders.

The MEP group calls on European policy-makers to:

- Support patient-led campaigns to educate, eradicate stigma and raise awareness of neurological and chronic pain disorders
- Support research into innovative prevention and treatments within a regulatory framework, facilitating equal access to affordable therapies
- Strengthen patient involvement in research, and policy-setting, and decision-making
- Implement European social legislation to ensure support for people living with neurological and chronic pain disorders

Four meetings are held annually to discuss topics in EFNA's Book of Evidence - the 20-page document outlining challenges and opportunities in the areas identified.

## AWARENESS

EFNA Executive Director Donna Walsh said: "To ensure future success for neurology advocates, we realised we needed to help



Above: IBTA Senior Advisor Jenny Baker at the European Parliament in Brussels. EFNA has a strong representation among Members of the European Parliament (MEPs) and works to raise awareness across Europe of all neurological diseases.

raise awareness of neurological disorders. Giving policy-makers and other audiences a better sense of incidence and impact could only strengthen our advocacy asks."

In 2016, EFNA launched its *Together under the Umbrella* campaign to increase public, political and scientific support for brain and brain-related disorders, and to reduce stigma.

The patient community, general public, and VIPs are asked to share photographs of themselves under an umbrella using the hashtag #UnderTheUmbrella.

The campaign aims to:

1. **Educate** on the wide range of neurological and other brain/brain-related illnesses

2. **Raise awareness** of the impact and prevalence of neurology disorders

3. **Brand the brain** by grouping conditions under a common symbol to create a 'brand'

The campaign was originally planned to run for a year to March 2017. However, its success and ongoing support from EFNA members means the campaign will continue and be integrated into EFNA's wider communications. The IBTA supports the aims of this campaign and hopes to become more involved in future. The campaign will also be active around World Brain Day, July 22nd, to be used as a platform for publishing patient stories. Information on how IBTA supporting groups can get involved will be provided nearer the date.

## EMPOWERMENT

In 2016, EFNA launched its 'Training Initiatives for Neurology Advocates' (TINA).

Having previously run workshops at the London School of Economics on Health Technology Assessment and Pharmaceutical Policy – Pricing, Access and Reimbursement, EFNA is now offering training for patient advocates to address the everyday challenges they face in their work and to ensure they have the skills, tools and local knowledge to apply the learning from high-level workshops elsewhere.

In 2017, the workshops will be focussed on communications, with a pan-European event on 3 and 4 May in Brussels, Belgium to explore 'Effective External Ambassadorship'. Other national workshops are planned in Romania on 9 June and Poland and Spain in autumn/winter 2017. EFNA will also continue to provide training



**Above:** Jenny Baker (right) with fellow Trustees of the European Federation of Neurological Associations – Monika Benson (left) of Dystonia Europe and Nancy Van Hoylandt (centre) of The European ME Alliance. The trio were at the European Parliament campaigning on behalf of the MakeWorkWork declaration - jointly promoted by Pain Alliance Europe and EFNA - for those affected by neurological disorders and chronic pain conditions

to members, such as its Governance Workshop which was held in March 2017.

## ENGAGEMENT

EFNA engages with and understands the needs of its membership. It reaches out to prospective members and represents members' interests to external stakeholders as well as connecting with multi-stakeholder partners in areas of mutual interest. A key stakeholder is the European Academy of Neurology (EAN) with which, in 2016, EFNA signed a Memorandum of Understanding to formalise and acknowledge the two organisations' special working relationship.

EFNA has enabled meaningful patient involvement within EAN. In 2016 EFNA members participated in the EAN Training and Education Committee and Liaison Committee, in EAN's scientific panels, in a joint awareness session within their annual congress and at a booth in the exhibition centre.

For the 2017 EAN Congress EFNA plans to host a joint special session on: Advanced Treatment and Management – Eliciting Patient Preferences, and a public day exploring Palliative Care for Neurological Disorders including a session on brain tumours.

Apart from the Congress, throughout 2017 EAN, in cooperation with EFNA, will feature a member organisation's profile in the EAN monthly newsletter. The IBTA is pleased



**Above:** IBTA Advisor and EFNA Board Member Jenny Baker joins Copenhagen's iconic Little Mermaid in being "Together Under the Umbrella"

that its work will be profiled this way in the autumn, to coincide with International Brain Tumour Awareness Week.

EFNA represents its members at other organisations including:

- European Brain Council (EBC)
- European Patients Forum (EPF)
- European Society of Radiology - Patient Advisory Group (ESR – PAG)
- Patients and Consumer Working Party at the European Medicines Agency (PCWP)
- Think-Tank at the European Federation for Pharmaceutical Industry Associations (EFPIA)
- European Alliance for Access to Safe Medicines (EAASM)
- Europa-Bio Patients Bio-Forum
- BioPontis Alliance

Each year, EFNA is also invited to participate and present at other events including its members' activities. ■

This article was written with the kind assistance of Donna Walsh, Executive Director, European Federation of Neurological Associations.

For more information on EFNA see: [www.efna.net](http://www.efna.net)

For more information on the European Parliament's Interest Group on Brain, Mind and Pain Disorders see [www.brainmindpain.eu](http://www.brainmindpain.eu)

For further details of EFNA's Together Under the Umbrella campaign see [www.undertheumbrella.eu](http://www.undertheumbrella.eu)



**Above:** Members of the Team In Memory of McGonigle

## Amazing amount of walked miles to raise awareness of brain tumors!

BREAKTHROUGH for Brain Tumors Run & Walk (BT5K) is the American Brain Tumor Association's (ABTA) national signature fundraising event. The BT5K events provide the opportunity to bring together the brain tumor community to raise awareness and funds for this worthy cause.

In 2016, ABTA walkers amassed an amazing amount of walked mileage at these events. Nearly 8,000 walkers achieved 24,629 miles which was symbolically donated to the IBTA's Walk Around the World for Brain Tumours.

In 2017, there will be nine ABTA "Breakthrough for Brain Tumors" events taking place, coast to coast, in America. ■



**Above:** BT5K volunteers prior to the Dallas event.

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# It's Lovely Down Under!

Mary Lovely, PhD, RN, CNRN

San Francisco, California, United States

SEVERAL years ago, I was asked to speak in Australia on brain tumor patient support issues. While planning the trip we also included New Zealand since these countries are relatively close. This vision finally came to fruition between 7 September and 24 September 2016. I had the privilege of connecting with so many people about brain tumor issues. Thank you to Brain Tumour Alliance Australia (BTAA) for funding my overseas plane fare and room expenses. Thank you to the Cancer Society of New Zealand, who opened up the New Zealand speaking tour. This truly was a grand opportunity that I will always remember.

For this tour, I prepared two lectures. These lectures included The Changing Care Needs for the Patient and Caregivers throughout the Brain Tumor Journey, and Patient Reported Outcomes. I gave these lectures at different venues. Here are some highlights of the trip.

## A busy time in Australia

The 2016 Asian Society of Neuro-Oncology (ASNO) and Cooperative Trials Group for Neuro-Oncology (COGNO) joint meeting was the first time that treatment strategies and patient support for neuro-oncology patients were included in the program. I gave a lecture on Patient-Reported Outcomes in the Quality of Life section. In the allied health care section, attended by nurses and doctors, several people lectured on interesting aspects of patient care. I spoke about Changing Care Needs. In addition, several nurses and other healthcare providers presented posters about patient-centered care. We had very good dialogue. I participated in several panel discussions and represented the patient support aspect, which brought greater awareness to total patient and family needs. My hosts from the BTAA (Susan Pitt, Catherine Hindson, Philip Steel,



Above: Mary Lovely and Chris Tse (IBTA Senior Advisor from New Zealand)

Tricia Berman) and the International Brain Tumour Alliance (Sally Payne and Chris Tse) were all so gracious.

Following Sydney, I traveled to Canberra, the capital of Australia. A group of nurses attended my lecture on Changing Care Needs. Most nurses were generalists, yet I met some nurses

deeply involved in caring for brain tumor patients and families. They carried a big load and were glad to talk with others who understood the effects of living with a brain tumor. In addition to the lecture, my hosts and I toured Canberra, including the Parliament Building. I also met up with Denis Strangman (formerly of the IBTA).

## A great New Zealand welcome

Several districts of the New Zealand Cancer Society sponsored me. This organization provides counseling and resources for brain tumor patients and families as there is no specialty brain tumor group in that country. They arranged for my hotel, and transportation. Cancer Society employees greeted me with cheerful hospitality at every engagement. My first lecture took place in Auckland at the Domain Lodge, a residence for patients and families receiving cancer treatment. Nurses and other health care professionals attended. They asked some very good questions. My next lecture was in Hamilton, a small town two hours by car south of Auckland. I spoke to



Above: In the New Zealand sunshine. Left to right: Chris Tse (IBTA Senior Advisor), Dr Mary Lovely, RN, CNRN, and nurses Anna Sisley and Julie Holt (Cancer Society of New Zealand, Wellington division).



Above: Mary presenting on The Changing Needs of the Patient and Family at Wellington Hospital, New Zealand

nurses and social workers who had little experience with brain tumor patients, so this information proved to be novel.

I flew to Wellington and was warmly greeted by Chris Tse, an International Brain Tumor Alliance Senior Advisor. Together with the Wellington division of the New Zealand Cancer Society, he organized the New Zealand section of this trip.

Chris and his wife, Lynda (who is an eleven year glioblastoma survivor – the IBTA covered her story in the 2014 edition of *Brain Tumour* magazine), showed me the beautiful sights of Wellington. I was intrigued with this town, and would love to return. He introduced me to Julie Holt, the Senior Information Nurse with the Cancer Society in Wellington. She accompanied me to lecture sites. The evening I arrived, I spoke at the Otago University Medical School to nurses and doctors about The Changing Needs of the Patient and Family. Dr. David Hamilton, an oncologist who cares for many brain tumor patients, introduced me and opened a lively discussion after the talk. In another lecture to healthcare professionals, for Journal Club at the Wellington Blood and Cancer Center, I spoke about patient reported outcomes. The group was interested in how patient reported outcomes could be used in daily practice.

Lectures targeted to patients and families in New Zealand were very rewarding. One lecture was held in Kapiti,



Above: The 2016 Asian Society of Neuro-Oncology (ASNO) and Cooperative Trials Group for Neuro-Oncology (COGNO) joint meeting in Sydney, Australia. From left to right: Mary Lovely, Sally Payne (IBTA Senior Advisor) and Philip Steel (Brain Tumour Alliance Australia - BTAA)



Above: Mary presenting on The Changing Needs of the Patient and Family at Wellington Hospital, New Zealand

a small beach town several miles north on the Western coast, and one in Wellington at the Cancer Society headquarters. In both cases, while talking about the changing needs of brain tumor patients and families, some people reached out for help with coping and brain tumor resources. Many of these people lived with symptoms or struggled with caregiving and did not know they could get help. Julie Holt worked with them, and made future appointments to provide further guidance. She and her team said they would follow up with these individuals. We were struck by the immediate impact of providing people with information about brain tumors and their similarly immediate

response for help. We felt this team effort of my lecture and Julie's quick response to patient and family needs was a very strong approach. It would be interesting to try this approach in other communities.

### In summary

Visiting Australia and New Zealand proved to be a very special experience for me. I met so many dedicated individuals, and spread the word about the importance of patient support. We reaped the benefits of collaborating between individuals and organizations focused on helping brain tumor patients and their families. Every moment was time well spent. ■



# Japan Brain Tumor Alliance (JBTA) hosts a patient and family information exchange and study session in Tokyo

Hisato Tagawa and Laureline Gatellier

Japan Brain Tumor Alliance (JBTA)

ON 18 February 2017 at 2.00 pm, the JBTA (Japan Brain Tumor Alliance) organized an information exchange and study session with brain tumor patients and their families in the Medical Department building of Keio University located in Tokyo, Japan. Forty patients and families attended the event.

The topics of the session were the following:

- Latest updates of research activities on cancer stem cells' (CSCs) characterization, which play a key role in the proliferation of tumors, and the development of new effective therapeutic approaches toward CSCs, based on the research of Dr. Hideyuki Saya, Professor, Division of Gene Regulation, Graduate School of Medicine, Keio University.

- Feedback and latest updates, from a patient perspective, of the SNO (Society for Neuro-Oncology) Annual Meeting by Laureline Gatellier, regular member of JBTA, who attended the SNO meeting on 16-19 November 2016 in Scottsdale, Arizona, USA.

- Latest brain tumor information obtained at SNO including the 2016 major re-classification of the World Health Organisation's (WHO) brain tumor grading, followed by some insight on the impact of this new WHO grading on the diagnosis of brain tumors, by Dr. Hikaru Sasaki, Associate Professor, Department of Neurosurgery, Keio University School of Medicine, and board member of Japan Society for Neuro-Oncology, who also attended SNO.

The presentations were followed by a question and answer session and by an exchange working dinner with patients and families, a great opportunity for newly-diagnosed and longer term patients to share thoughts and feelings. ■

平成29年2月18日(土)14時から慶応大学医学部総合医科学研究棟に於いて脳腫瘍の患者家族のための交流会・勉強会を開催しました。参加者は40名でした。勉強会の内容としては、

1. 慶応大学医学部先端医科学研究所遺伝子制御研究部門教授の佐谷秀行先生から、がん細胞の中で特に中心的な役割を果たす癌幹細胞と、その他の癌細胞について女王バチと働きバチの例になぞらえて、その働きや相互関係を分かりやすくご説明頂きました。また、その癌幹細胞に効果が期待される治療薬剤の候補として挙げられているスルファサラジンについて、先生ご自身の研究結果から最新の知見をご紹介して頂きました。

2. 東京都在住の脳腫瘍ネットワークの正会員であり、昨年11月アメリカで開催のSNO (Society for Neuro-Oncology Annual meeting 16-19 Nov. 2016 Scottsdale, AZ, USA)

に参加されたガテリエ・ローリンさんから、学会の参加報告として、患者側から見た学会の様子や最新の情報をお話しいただきました。

3. 慶応大学病院脳神経外科(日本脳腫瘍学会理事)佐々木光先生から、SNOで得られた、脳腫瘍に関する最新の情報とWHOのグレード分類の変更のことなどをお話し頂き、WHOの分類については今後の脳腫瘍の診断にどのように影響するのかを教えて頂きました。

その後、質問と患者家族による交流会を行い、発表内容について話し合うとともに、新たな会員や旧知の方々との交流を深めました。■

Right: Prof. Hideyuki Saya giving a presentation on his own basic research activities and the future prospect of glioma management based on personal research

佐谷秀行先生が先生ご自身の神経膠腫に関する基礎研究結果と、それに基づく今後の展望について発表されました



Above: Laureline Gatellier sharing her learnings from a patient perspective, after her attendance at SNO (the Society for Neuro-Oncology annual meeting) held in November 2016

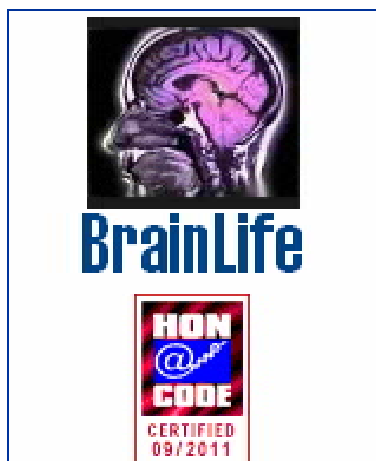
ガテリエ ローリンが2016年11月に開催された米国の脳腫瘍学会(SNO)に参加し、そこで得られた最新の知見を患者の立場で発表しました。



Above: Dr. Hikaru Sasaki, who also attended SNO 2016, sharing his scientific knowledge regarding the new WHO classification of brain tumors and the results of clinical research presented at SNO 同じくSNOの学会に参加された佐々木光先生が、学会で発表されたWHOの新たな脳腫瘍の分類と臨床試験の結果について科学的な見地から発表されました。







**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**.

Lithuanian community  
**"Kartu lengviau"**  
 (engl. "Easier together")  
 unites brain tumour patients  
 and their relatives

Please, contact us: **+370 616 26324**  
**info@kartulengviau.lt**  
**www.kartulengviau.lt**

## hersentumor contactgroep



## hersenletsel.nl

Supportgroup Braintumors The Netherlands

[www.kanker.nl/organisaties/werkgroep-hersentumoren](http://www.kanker.nl/organisaties/werkgroep-hersentumoren)

[johndebruin@hersenletsel.nl](mailto:johndebruin@hersenletsel.nl)

[jelledevries@hersenletsel.nl](mailto:jelledevries@hersenletsel.nl)

Meningioma UK [www.meningioma.uk.org](http://www.meningioma.uk.org)  
 21 Plough Lane, Sudbury, Suffolk CO10 2AU  
 Helpline: 01787 374084 Email: [support@meningioma.uk.org](mailto:support@meningioma.uk.org)  
 Reg Charity No: 10071452



**MeningiomaUK**  
 Brain Tumour Support

**We are the national support group, founded and run by meningioma patients, for everyone affected by meningeal tumours of the brain or spinal cord.**

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**Web: [www.meningioma.org](http://www.meningioma.org)**

**Email: [support@meningioma.uk.org](mailto:support@meningioma.uk.org)**

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# Brain tumour patient and caregiver advocacy, support, fundraising and information organisations and initiatives

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## AUSTRALIA

ACT Brain Tumour Network  
Email [btaa@shout.org.au](mailto:btaa@shout.org.au)  
or call Susan on 0404255156

Adult Brain Cancer Support Association  
[adultbraincancersa@gmail.com](mailto:adultbraincancersa@gmail.com) <https://www.facebook.com/AdultBrainCancerSA?fref=nf>

Australian Pituitary Foundation  
<http://www.pituitary.asn.au/>

Brain Tumour AhoyHoy  
<http://www.braintumourahoyhoy.org/>

Brain Tumour Alliance Australia (BTAA)  
[www.btaa.org.au](http://www.btaa.org.au)

Brain Tumour Association Western Australia  
[braintumourwa@hotmail.com](mailto:braintumourwa@hotmail.com)  
<http://www.btawa.com.au/>

Brain Tumour Support Group - Cancer Council Queensland  
<https://cancerqld.org.au/get-support/>  
or <https://cancerqld.org.au/get-support/cancer-emotional-support/brain-tumour-support/>

Cure Brain Cancer Foundation  
<http://www.curebraincancer.org.au>

Grey Matters  
[www.greymatters.org.au](http://www.greymatters.org.au)

Neuro-Oncology Information Network - NOgIN  
<http://www.sydneybrainandspinesurgeons.com.au/nogin.html>

Newro Foundation  
<http://www.newrofoundation.com.au/>

Peace of Mind Foundation  
<http://www.peaceofmindfoundation.org.au>

Robert Connor Dawes Fund  
<http://rcdfoundation.org/>

United Brain Tumour Support  
Contact Pete McLaughlin:  
(Australia) 0422 784885.  
Listing here also: <http://www.yourcare.com.au/supplier/profile/united-brain-tumour-support>

## BELGIUM

Can cé tu  
<http://www.cance-tu-asbl.eu>

Werkgroep Hersentumoren  
<http://www.wg-hersentumoren.be>

## CAMEROON

Jacob's Hope Foundation  
<https://www.facebook.com/Jacobs-Hope-Foundation-for-Brain-tumours-and-other-cancers-1735452683351613/>

## CANADA

BC Cancer Agency  
<http://www.bccancer.bc.ca>

B-Strong  
<http://www.bstrong.ca>

b.r.a.i.n.child  
<http://www.sickkids.ca/Brainchild/index.html>

Brain Tumour Foundation of Canada  
[www.braintumour.ca](http://www.braintumour.ca)

Gerry and Nancy Pencer Brain Tumor Centre  
<http://www.pencerbraintrust.com/>

Joe di Palma Brain Tumor Foundation  
[www.joedipalmafoundation.com](http://www.joedipalmafoundation.com)

Meagan's Walk: Creating a Circle of Hope  
[www.meaganswalk.com](http://www.meaganswalk.com)

Tali's Fund  
[www.taldoron.com](http://www.taldoron.com)

## CAYMAN ISLANDS

Brain Tumour Foundation (Cayman Islands)  
"The Forgotten"  
<http://www.btfcaymanislands.com>

## CROATIA

Croatian Brain Tumor Association - GLIA  
[www.glia.hr](http://www.glia.hr)

## CYPRUS

Cyprus Brain Tumour Association (CBTA)  
<https://www.facebook.com/cbta.cyprus>

## DENMARK

HjernetumorForeningen  
<http://www.cancer.dk/hjernetumorforeningen/>

## EL SALVADOR

Gris Positivo  
<http://grispositivo.org>

## FRANCE

Alinoe (Association Lilloise de Neuro-Oncologie)  
[www.alinoe.asso.fr](http://www.alinoe.asso.fr)

ARTC Paris  
<http://www.artc.asso.fr/>

ARTC Sud  
[www.artcsud.fr](http://www.artcsud.fr)

ARTC Toulouse – Midi Pyrenees  
<http://www.artc.asso.fr>

Association Léa Princesse Eternelle  
<http://leapourlavie.free.fr/>

GFME Glioblastoma Fondation Michèle Esnault  
<http://gfme.free.fr/>

Imagine for Margo  
<http://imagineformargo.org/en>

Oscar's Angels  
[www.oscarsangels.com](http://www.oscarsangels.com)

## GERMANY

Deutsche Hirntumorhilfe eV  
[www.hirntumorhilfe.de](http://www.hirntumorhilfe.de)

## INDIA

Brain Tumour Foundation of India  
[www.braintumourindia.org](http://www.braintumourindia.org)

## IRELAND

Brain Tumour Ireland  
<http://www.braintumourireland.com/bti/>

The Irish Brain Tumour Support Group  
[www.irishbraintumoursupport.org](http://www.irishbraintumoursupport.org)

## ITALY

Associazione Italiana Tumori Cerebrali ONLUS  
<http://www.tumoricerebrali.it/>

BrainLife  
[www.brainlife.org](http://www.brainlife.org)

Il Fondo di Gio ONLUS  
[www.ilfondodigio.it](http://www.ilfondodigio.it)

IRENE Onlus  
<http://www.associazioneirene.it/>

Italia - Glioblastoma Multiforme - cancro al cervello  
<https://www.facebook.com/Italia-Glioblastoma-multiforme-cancro-al-cervello-57560022151/>

## JAPAN

Japan Pediatric Brain Tumor Network  
[www2.pbtn.jp](http://www2.pbtn.jp)

Japan Brain Tumor Alliance  
<http://www.jbta.org>

## LEBANON

CHANCE - Children AgaiNst CancEr  
<http://www.beirut.com/l/25407>

## LITHUANIA

Kartu Lengviau  
[www.kartulengviau.lt/joomla/pradzia.html](http://www.kartulengviau.lt/joomla/pradzia.html)

## NETHERLANDS

Hersentletsel.nl  
<http://www.hersenletsel.nl>

Hersentumor.nl  
<http://hersentumor.nl/>

STOPhersentumoren.nl  
[www.stophersentumoren.nl](http://www.stophersentumoren.nl)

## NORWAY

Hjernesvulstforeningen  
[www.hjernesvulst.no](http://www.hjernesvulst.no)

## PHILIPPINES

Philippines Brain Tumour Alliance  
<http://www.facebook.com/pages/Philippine-Brain-Tumor-Alliance/139492062749160/>

## SINGAPORE

Brain Tumour Society (Singapore)  
<http://braintumoursociety.org.sg>

## SOUTH AFRICA

Rainbows and Smiles  
<http://www.rainbowsandsmiles.org.za>

## SPAIN

Association Española de Afectados por Tumores Cerebrales - ASATE  
<http://www.asate.es/>

Fondo Alicia Pueyo - The Alicia Pueyo Fund  
[www.fondoaliciapueyo.org](http://www.fondoaliciapueyo.org)

## SWEDEN

Swedish Brain Tumor Association (Svenska hjärntumörföreningen)  
[www.hjarntumorföreningen.se](http://www.hjarntumorföreningen.se)

## SWITZERLAND

Kinderkrebs Schweiz  
<http://www.kinderkrebshilfe.ch>

Schweizer Hirntumor Stiftung (Swiss Brain Tumor Foundation)  
<http://www.swissbraintumorfoundation.com>

## TAIWAN

Childhood Brain Tumour Association of Taiwan (CBTA)  
<http://www.cbta.org.tw>

## TURKEY

Türkiye Beyin Tumoru Hasta ve Yakınları Derneği (Brain Tumour Patient & Caregivers' Association of Turkey)  
<https://www.facebook.com/tbthyd/>

## UGANDA

Uganda Brain Tumour Foundation  
<http://www.ubtuf.org>

## UNITED KINGDOM

Ali's Dream  
[www.alisdream.co.uk](http://www.alisdream.co.uk)

Andrew McCartney Trust Fund  
[www.andrewmccartneyphotos.co.uk](http://www.andrewmccartneyphotos.co.uk)

Anna's Hope  
[www.annashope.co.uk](http://www.annashope.co.uk)

Astro Brain Tumour Fund  
[www.astrofund.org.uk](http://www.astrofund.org.uk)

Brain and Spine Foundation  
[www.brainandspine.org.uk](http://www.brainandspine.org.uk)

Brain Tumour Action  
[www.braintumouraction.org.uk](http://www.braintumouraction.org.uk)

Brain Tumour Research  
[www.braintumourresearch.org](http://www.braintumourresearch.org)

Brain Tumour Research and Support Across Yorkshire  
<http://www.btrs.org.uk>

Brain Tumour Research Campaign  
<http://www.wayahead-btrc.org/>

Brain Tumour Support  
[www.braintumoursupport.co.uk](http://www.braintumoursupport.co.uk)

Brain Tumour Support Group - St Thomas' Hospital, London  
<http://www.guysandstthomas.nhs.uk/our-services/cancer/cancer-types/brain/patients.aspx>

Braintrust  
[www.braintrust.org.uk](http://www.braintrust.org.uk)

Brainwaves Brain Tumour Support Group  
<http://www.brainwavessg.co.uk/>

Brainwaves NI (Northern Ireland)  
[www.brainwaves-ni.org](http://www.brainwaves-ni.org)

British Acoustic Neuroma Association - BANA  
[www.bana-uk.com](http://www.bana-uk.com)

BT Buddies  
[www.btbuddies.org.uk](http://www.btbuddies.org.uk)

Charlie's Challenge  
[www.charlieschallenge.com](http://www.charlieschallenge.com)

Clowns in the Sky  
<http://www.clownsinthesky.org/>

East Kent Brain Tumour Support Group  
<https://www.facebook.com/EKBTSG/>

Ed Evans Foundation  
[www.edevansfoundation.co.uk](http://www.edevansfoundation.co.uk)

Ellie's Fund - Brain Tumour Trust  
[www.elliesfund.com](http://www.elliesfund.com)

Fighting Ependymoma  
<http://www.fightingependymoma.org.uk>

Headcase  
[www.headcase.org.uk](http://www.headcase.org.uk)

Katie McKerracher Trust  
[www.katiemckerrachertrust.co.uk](http://www.katiemckerrachertrust.co.uk)

Levi's Star  
<http://www.freewebs.com/levisstar/>

Meningioma UK  
[www.meningiomauk.org](http://www.meningiomauk.org)

Naseem's Manx Brain Tumour Charity  
<http://www.naseemsmnxbraintumourcharity.co.uk/>

PPR Foundation  
<http://www.thepprfoundation.com/>

Spinal Cord Tumour Forum  
[www.spinalcortumour.org.uk](http://www.spinalcortumour.org.uk)

Taylan's Project  
[www.taylansproject.com](http://www.taylansproject.com)

Teenage Cancer Trust  
[www.teenagecancertrust.org](http://www.teenagecancertrust.org)

The Brain Tumour Charity  
[www.thebraintumourcharity.org](http://www.thebraintumourcharity.org)

Thorne Mason Trust  
<http://www.thornemasontrust.co.uk/>

Tuberous Sclerosis Association  
[www.tuberous-sclerosis.org](http://www.tuberous-sclerosis.org)

Worcestershire Brain Tumour Support Group  
<http://www.braintumoursupport.co.uk/worcestershire.html>

## UNITED STATES

Accelerate Brain Cancer Cure  
[www.abc2.org](http://www.abc2.org)

Addi's Faith Foundation  
[www.addisfaithfoundation.org](http://www.addisfaithfoundation.org)

Adult Ependymoma  
<https://sites.google.com/site/adultependymoma/>

A Kid's Brain Tumor Cure (AKBTC)  
<http://akidsbraintumorcure.org>

American Brain Tumor Association (ABTA)  
[www.abta.org](http://www.abta.org)

Angels Among Us  
[http://dccc.convio.net/site/PageServer?pagename=angels\\_home](http://dccc.convio.net/site/PageServer?pagename=angels_home)

Ben and Catherine Ivy Foundation  
[www.ivyfoundation.org](http://www.ivyfoundation.org)

Benny's World  
<http://www.bennysworld.org/>

Brad Kaminsky Foundation  
[www.tbkf.org](http://www.tbkf.org)

Brain Candy Project  
[www.braincandyproject.org](http://www.braincandyproject.org)

Brain Science Foundation  
[www.brainsciencefoundation.org](http://www.brainsciencefoundation.org)

Brain Tumor Foundation  
[www.braintumorfoundation.org](http://www.braintumorfoundation.org)

Brain Tumor Foundation for Children  
[www.braintumorkids.org](http://www.braintumorkids.org)

Brain Tumor Fund for the Carolinas  
<http://www.btfnc.org/about/overview.cfm>

Brain Tumor Support Group of Northeast Florida  
<http://resources.caregiver.com/listing/brain-tumor-support-group-of-northeast-florida.html>

Brains Together for a Cure  
[www.brainstogetherforacure.org](http://www.brainstogetherforacure.org)



Brian Bedell 2 Young Foundation  
<http://www.2yf.org>

BT Survivor Online Group  
[www.btsurvivor.com](http://www.btsurvivor.com)

California Brain Tumor Association  
<https://www.facebook.com/The-California-Brain-Tumor-Association-217285898326170/>

Central Brain Tumor Registry of the United States  
<http://www.cbtrus.org/>

Central New Jersey Brain Tumor Support Group – CNJBTS  
[www.njbt.org/startCNJBTS.cfm](http://www.njbt.org/startCNJBTS.cfm)

Charles Warren  
Brain Tumor Awareness Foundation  
[www.charleswarrenfoundation.org](http://www.charleswarrenfoundation.org)

Childhood Brain Tumor Foundation  
[www.childhoodbraintumor.org](http://www.childhoodbraintumor.org)

Children's Brain Tumor Foundation  
[www.cbtf.org](http://www.cbtf.org)

Chordoma Foundation  
<http://www.chordomafoundation.org>

Chris Elliott Fund/EndBrainCancer Initiative  
[www.chriselliottfund.org](http://www.chriselliottfund.org)

Collaborative Ependymoma Research Network (CERN) Foundation  
<http://cern-foundation.org>

Cullather Brain Tumor Quality of Life Center  
<http://cullather.org/>

Dr Mamie Rose Foundation  
[www.drmamierose.org/](http://www.drmamierose.org/)  
<https://www.facebook.com/drmamierosefoundation/>

Emory Brain Tumor Support Group  
[www.neurosurgery.emory.edu/BTSG/contact.htm](http://www.neurosurgery.emory.edu/BTSG/contact.htm)

Ependyaparents online support group  
<http://braintrust.org/groups/ependyaparents/>

Epidermoid Brain Tumor Society (Online)  
<http://epidermoidbraintumorsociety.org/>

Florida Brain Tumor Association  
<http://www.floridabraintumor.com/homepage.htm>

Gray Matters Foundation  
[www.graymattersfoundation.com](http://www.graymattersfoundation.com)

Head for the Cure Foundation  
[www.headforthecure.org](http://www.headforthecure.org)

Healing Exchange Brain Trust  
<http://braintrust.org>

Jeffrey Thomas Hayden Foundation  
[www.jthf.org/](http://www.jthf.org/)

Just One More Day:  
<http://dipg.blogspot.co.uk/>

Kevin J Mullin Memorial Fund  
for Brain Tumor Research  
[www.lemonhead.org/](http://www.lemonhead.org/)

Kortney Rose Foundation  
<http://thekortneyrosefoundation.org/>

Lauren's Foundation  
<http://laurensfoundation.org/fitzys-5k-run/>

Legacy Brain Foundation  
<http://www.legacybrainfoundation.com/>

Making Headway  
[www.makingheadway.org](http://www.makingheadway.org)

Mark Linder Walk for the Mind  
<http://www.marklinderwalkforthemind.org/>

mASS Kickers  
<http://www.masskickers.org/>

Matthew Larson  
Pediatric Brain Tumor Research Foundation  
[www.ironmatt.org](http://www.ironmatt.org)

Matthew's Miles  
<http://www.matthewsmiles.org/>

Meningioma Mommas  
[www.meningiomamommas.org](http://www.meningiomamommas.org)

Michael G Belz Foundation  
<http://mgbf.org>

Michael Quinlan Brain Tumor Program/  
Brain Injury Association of Kentucky  
[www.biak.us](http://www.biak.us)

Monmouth and Ocean County  
Brain Tumor Support Group  
[www.njbt.org/startMOCBTSG.cfm](http://www.njbt.org/startMOCBTSG.cfm)

Musella Foundation for Brain Tumor Research and  
Information, Inc.  
[www.virtualtrials.com](http://www.virtualtrials.com)

National Brain Tumor Society  
[www.braintumor.org](http://www.braintumor.org)

Nick Gonzalez Foundation for Brain Tumor Research  
<http://thenickgonzalesfoundation.org/>

Oklahoma Brain Tumor Foundation  
[www.okbtf.org](http://www.okbtf.org)

Pediatric Brain Tumor Foundation  
<http://www.curethekids.org/>

ROC On! Run Over Cancer  
<http://www.roconnow.com/>

San Diego Brain Tumor Foundation  
[www.sdbtf.org](http://www.sdbtf.org)

Sontag Foundation and Brain Tumor Network  
(BTN)  
<https://sontagfoundation.org>  
<http://www.braintumornetwork.org>

Southeastern Brain Tumor Foundation  
<http://sbtbf.org/>

Students Supporting Brain Tumor Research  
(SSBTR)  
<http://www.ssbtr.org/>

Team Billy  
[www.teambilly.org](http://www.teambilly.org)

The Caroline Fund  
<http://www.carolinefund.org>

The Cure Starts Now Foundation  
[www.thecurestartsnow.org](http://www.thecurestartsnow.org)

The Tanner Seebaum Foundation  
[www.tannersfoundation.org](http://www.tannersfoundation.org)

Tug McGraw Foundation  
<http://www.tugmcgraw.org>

Voices Against Brain Cancer  
[www.voicesagainstbraincancer.org](http://www.voicesagainstbraincancer.org)

Walk for Kate and Blankets for Brains  
<http://www.walkforkate.org/about.html>

We Can Pediatric Brain Tumor Network  
[www.wecan.cc/We\\_Can/Home.html](http://www.wecan.cc/We_Can/Home.html)

Western North Carolina Brain Tumour Support  
[www.wncbraintumor.org](http://www.wncbraintumor.org)

## ZIMBABWE

Zimbabwe Brain Tumor Association (ZBTA)  
<https://www.facebook.com/Zimbabwe-Brain-Tumor-Association-225796887464934/>



and the

**INTERNATIONAL  
BRAIN TUMOUR  
AWARENESS WEEK**

1 January - 31 December 2017

21 - 28 October 2017

These two projects are being repeated for the eleventh year in a row in 2017.  
The IBTA requires no financial commitment from your organisation to be a supporter.  
Contact [chair@theibta.org](mailto:chair@theibta.org)

**YOUR SUPPORT OF THESE TWO POPULAR GLOBAL EVENTS WILL FURTHER HELP  
BRAIN TUMOUR PATIENTS TO DEAL WITH THE CHALLENGES THEY FACE.**

# BRAIN TUMOURS

URGENTLY  
NEEDED:

MORE  
RESEARCH  
AND SUPPORT



INTERNATIONAL  
BRAIN TUMOUR  
ALLIANCE

[www.theibta.org](http://www.theibta.org)

International Brain Tumour Awareness Week:  
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