Riding the crest of a wave towards greater awareness of brain tumours

MATT PITT
Chair of Brain Tumour Alliance Australia, brain tumour survivor (Australia)

I am Chair of Brain Tumour Alliance Australia (BTTA), the only national advocacy group for patients and caregivers in Australia. I have been doing this work for around one and a half years. In 2001, I was diagnosed with a 3rd ventricular pilocytic astrocytoma, and was very sick at the time as a result of its large size and position, and consequential severe hydrocephalus. I was 19 at the time, and in hindsight had been suffering detrimental effects from the tumour for at least five years. My friends were in the first or second year of university and beginning their adult lives, while I was dependant on my parents and living at home. I felt completely alone, and that cognitive deficits had made my life not worth living. In particular, my anterograde memory was very clear, and “retrograde” memories, see http://en.wikipedia.org/wiki/Retrograde_ amnesia] though grateful that my tumour was benign, it took me many years to feel any enjoyment in my life and look forward to the future. I became resentful when well-meaning friends and family would tell me everything was ok, and that they could see no change in my personality or functioning. I felt that I had died at 19, and in the time since had inherited a second, greatly diminished life barely worth living. In 2003, I underwent further surgery for residual tumour. Throughout the process, I was struck by the lack of information provided to brain tumour patients, and in particular information on the services available for their treatment. I was very fortunate in understanding my treatment options, but this only came about because medical connections in my family helped me to navigate the system. Around this time, my mother Susan Pitt, joined other caregivers and patients in forming Brain Tumour Australia, which has since disbanded, and I would occasionally participate in local activities run by them. I was also asked to speak at the 2004 Parliamentary inquiry into services and treatment options for persons with cancer as part of the submission by Brain Tumour Australia. When I was very sick in 2001 and 2003, I found that slow jogging helped reduce headaches resulting from hydrocephalus and surgery. Since that time, I have found that low impact sports such as cycling and swimming are more enjoyable. Every now and again, I get to go surfing at the New South Wales coast.  The first three items on my wish list for brain tumour patients would be: (1) a cure for all brain tumours: (2) Upon diagnosis, their receipt of a comprehensive information package containing information about the relevant type of brain tumour, the area of brain affected, possible cognitive and emotional changes to expect, treatment options, support groups in their area, and online and telephone contacts where they can receive more information; (3) a widespread understanding by the wider community of the disease, and the difficulties faced by patients and caregivers living with it. When I was very sick in 2001 and 2003, I found that slow jogging helped reduce headaches resulting from hydrocephalus and surgery. Since that time, I have found that low impact sports such as cycling and swimming are more enjoyable. Every now and again, I get to go surfing at the New South Wales coast. 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O n October 29, 2006, I had a focal seizure. In my mind I thought I was having a stroke given my weight and once-in-a-blue-moon athletic lifestyle right after marriage. My face and mouth twitched to the right for about one minute and thirty- one seconds. I was rushed to the ER of a nearby hospital and my blood pressure was 200/130 and they also find out I have type two diabetes. I was fully rested, with no stressful reason to be. There were times when I was working graveyard shift serving U.S. Verizon DSL customers when I was diagnosed with a tumor. Simultaneously I spoke, taught, counseled in the community. I got gratuities when I performed these activities.

I was working graveyard shift serving U.S. customers for eight months before my first seizure and in close proximity with a computer as a TSR. About four or five months into that job, my right eye started to experience periodic twitching. I dismissed the experience as being tired. But there were frequent headaches a lot of which never had any reason to be. There were times when I was fully rested, with no stressful moments, yet a severe headache would inconvenience me for two to three hours.

After the medical diagnosis the company could not employ me in a technical job such as a TSR. I do a lot of public speaking like sharing in the community, church communities, teaching seminars, counseling, officiating at marriages, baby dedications. I cannot perform these anymore because I stammer a lot and cannot remember all the things I want to say unless I am glued to my script. After the awake craniotomy: The nature of the "tumor" only allowed my neurosurgeon Dr. Gerardo Legaspi to excise 60% which left 40% still in place. The remaining mass caused me 12 seizures of the same details and descriptions since the craniotomy up to this date. It was very difficult not knowing when and where I would have seizures although sometimes a hint of "an aura" signaled its occurring. Communication is a struggle especially when I want to participate in a group dialogue and conversations because of word generation although nothing with my memory. I can still drive, ride a bike, climb a mountain, travel and do a lot of activity although with some restrictions.

I do not receive adequate support since I lost the capacity to perform my job well. Some friends and family members send some money for the medications. Thank God one of our friends pays for my second son's schooling for his four year college course. He is on his last semester of a computer science course and will do his on-the-job-training soon. We are using up our savings. I cannot go back to work; my wife cannot work since she is my main caregiver.

In terms of a brain tumor patient support group, there is none. My wife and I regularly visit a government/public hospital mainly for the masses of Filipinos, Philippine General Hospital (PGH) Neurosurgery Section for the brain tumor patients. It started when Dr. Legaspi invited us to share our experience in the Charity Ward. We visited the ward to talk to the patients and their families, giving hope, encouraging them and giving them some tips they needed before, during and after surgery. We also pray for each one of them. Sometimes we bring a Bible and share some literature. We also sometimes bring some food to share with them.

We have not talked to any person with similar diagnosis. Patient privacy is well observed in the Philippines and we cannot obtain any information.

We wanted to start a Brain Tumor Association for Patients and Caregivers (families) but we do not know how. So we have asked IBTA if they can help us start. From among our circle of friends we have only two who are meningioma survivors, one of which used to join us to share her story.

Do I have any tips or suggestions for newly diagnosed brain tumor patients? Yes! Fight fear by knowing the FACTS about your tumor and its treatment. Communication is key especially when you want to participate in a group dialogue and conversations because of word generation although nothing with my memory. I can still drive, ride a bike, climb a mountain, travel and do a lot of activity although with some restrictions. Medical management focus and the physical challenge and adjustments should not deter or stop you from focusing on your life’s goals. Each day is a brand new day. After my surgery I climb the second highest mountain in the Philippines (Mt. Pulag) with my neurosurgeon.

Health and nutrition are vital in the medical management after brain tumor surgery. The patient and caregiver and the rest of the family should be pro-active in the medical management such as eating the same food for the proper nutrition of the patient. Pro-active also includes reading literature about the medicines taken, side effects and indications. I am so blessed to have my wife Susan who takes care of this vital matter. Remember to share hope with fellow brain tumor patients when you can.

I wish I could encourage young parents and their children to have a regular medical check up. We started early on with unhealthy living habits because of bad influence. Now I want to help. I am thankful to my wife who introduces me to healthy and nutritious food.

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DIPG TUMORS – ADVANCING KNOWLEDGE IN SPAIN

GLORIA GARCIA CASTELVI
Founder and Coordinator of Fondo Alicia Pueyo

I n the Coordinator of Fondo Alicia Pueyo. This fund was set up by our family in Hospital Sant Joan de Deu (Barcelona, Spain) for promoting and supporting research on childhood brainstem tumors. Our aim is helping to find a cure as soon as possible for this terrible disease.

Our activity was started in November 2008. Our daughter Alicia passed away from a diffuse intrinsic pontine glioma (DIPG) in November 2007, when she was seven years old. From that moment, my husband and I decided to support research into this kind of brain tumor, since very poor advances have been achieved in the last 30 years regarding treatments for these kids. Children diagnosed with DIPG have a very poor prognosis. Life expectancy is 12 months and more than 95% of them will die in the 18 months following diagnosis. Further research and initiatives are urgently needed to change this unacceptable scenario.

The biggest challenge of my work in the brain tumour community has been to organize the first DIPG International Workshop in Barcelona in February 2009. The research group which we are supporting in Barcelona is a very young one regarding DIPG research, and gathering a few of the best DIPG experts wasn’t easy. It was great to see all those researchers sitting around a table and talking about future collaboration to fight this disease and find a cure for these kids.

Another challenge has been to become known in the brain tumor community. It is not easy when you are a very small group and you aren’t from the UK or the US. In this case, to focus on DIPG has helped with this, since there are very few initiatives related to this tumor.

The first three items on my wish list for brain tumour patients would be: (1) to have access to the best medical care available, no matter where you live or the economic resources you have; (2) to have access to all the information about clinical trials or new drugs related to this type of tumor and (3) to have access to a support group which can help with the different problems that a brain tumor patient must face.

I don’t have any special hobby to relax. I like swimming, although I don’t do it a lot. I love travelling with my husband and son, discovering new places and countries, and spending time with them. When you have lost a very much loved one, you do realize how important is to be with them and to enjoy life together.

TREATING AN ORPHAN DISEASE

Dr ALBA BRANDES
Director of Medical Oncology, Bellaria-Maggiore Hospital, Bologna, Italy

IBTA: Where did you spend your childhood?
HW: Canberra. – “My parents moved there when I was three. Dad was in the Air Force so I was there until I moved to Sydney University at 18.”

IBTA: Did you come from a family environment that had a connection with medicine or research?
HW: Neither of my parents had a tertiary education. I have no medical connections whatsoever.

IBTA: What attracted you to medicine and, later, to the brain tumour area?
HW: My Dad bought a farm 60 miles from any civilization - or hospital. My original plan when I enrolled in medical school was to be a part-time country GP and run the farm. I really enjoyed medical training, and then decided to do oncology. Much to my disappointment, Dad sold the farm. There was no such thing as neuro-oncology when I trained. Patients were simply discharged post-op or referred to radiotherapy. We then got an enthusiastic group of young neurosurgeons who had just returned from the US who started to ask for consults. Completely out of my depth, I enrolled and went to a SNO (Society for Neuro-Oncology) meeting in San Francisco in the late 1990s. I must have looked very lost. I must have been one of the only “foreigners” there, and somehow got “adopted” by Skip Grossman, Jan Buckner and Greg Cairncross [three eminent neuro-oncology specialists]. The rest is history.

IBTA: How do you relax? Do you play music, go for walks, sail a boat? Do you have a hobby?
HW: I love to garden and have been a very keen fisherman in my time.

IBTA: How do you cope with the emotional and psychological challenges to you personally arising from your work?
HW: You just have to set limits. I think the next ten years will be very exciting for neuro-oncology. The technological advances that are infiltrating the labs at the moment are making everything so much quicker. Brain tumours have suddenly gone from “not interested” to a very hot topic with the big pharma companies (we only say about 20 years too late). I think we can expect very big changes in the near future. I see my role as trying to keep everyone well till they land in Australia, but unfortunately that is a big call at present.”

Dr Alba Brandes, Chairman of Medical Oncology, Bellaria-Maggiore Hospital, Bologna, Italy

Dr Alba Brandes, Coordinator of Fondo Alicia Pueyo, Spain, with her son and daughter Alicia, a few months before Alicia’s diagnosis of a DIPG brain tumor

Jan Geisler
The above is a photo of Jan Geisler, Director of the European Cancer Patients’ Coalition (ECP), which appeared on a recent issue of the magazine Cancer World. The IBTA has worked closely with Jan and the ECP, which now has over 300 member organisations from 41 countries worldwide.

Singapore

The IBTA Chair speaks at a meeting of the Singapore Brain Tumour Support Group, which is coordinated by Emily Ang (second from left in white uniform) of the National Neuroscience Institute.

The IBTA is grateful to Dr Carmine M Carapella (Italy) for facilitating the distribution of the IBTA booklet about the First Documented Modern-Day Operation for a Glioma to those attending the 2009 conference of the Italian Association of Neuro-Oncology (AION).
THE HIP-HOP KICKBOXER WHO GIVES CARE AND SUPPORT

Cindy Rosser
Michael Quinlan Brain Tumor Foundation

I work for the Michael Quinlan Brain Tumor Foundation (MQBTF) in the United States as Support Liaison. I have the duties of Case Manager, Resource Manager, Support Program Coordinator, Counsellor and Chaplain. On March 23, 2010 I will have been three years with MQBTF. My mom is a six and a half year meningioma survivor. We came to MQBTF through a friend of hers that was diagnosed with acoustic neuroma just two months prior. Today she is our RN Navigator, on the MQBTF Medical Advisory Board, and leads a support group for benign brain tumor survivors. She helps me keep up with our growing membership, particularly with newly diagnosed. With my background in pastoral counselling and the growing need in the MQBTF membership, our Director felt it was good timing for me to come on board. It was the right place and the right time.

I learned in seminary with my first clinical practicum that I can’t fix people, take control of a situation, or take any credit for success. There are days when I wish I could turn off the heartache, but I trust God to care for people and I pray for them. I do my best to leave my work at the office. It doesn’t always go that way because need is out of season, but I try, I know my limits. When I’m “full,” I admit it and turn the need over to someone else if I can.

My satisfaction (at work) is the reward that comes with the honor and privilege being in another soul’s “sacred circle,” as I call it. To be with a person and their family in a private time of need and crisis is sacred. To see need met and healing come about, realizing that healing comes in more ways than just the physical realm, thrills my soul!

While there are many success stories, there are just as many tales of hardship and heartache. I am human, and it’s hard not to carry the weight of sadness and desperation of unmet needs and terminal illness. People lose their homes, jobs and marriages. They lose hope and dignity. People suffer and die and grief is overwhelming. My biggest challenge is to offer hope. I’m humbled daily by the heroism around me and my inadequacy.

Cindy Rosser of the Michael Quinlan Brain Tumor Foundation

The first three items on my wish list for brain tumour patients would be: (1) a cure; (2) money and insurance to cover all expenses and (3) the God of hope to be very real in their lives.

I make time for friends and family remembering that they have needs too, and I need them. I walk and garden. I am a nature lover. I enjoy cooking. I work out at Urban Active Fitness five days per week and have a regular routine of resistance training and Zumba. Sumba is Latin pop aerobic dance. It’s fun and very vigorous exercise. I do hip-hop aerobics and kickboxing too. I love it! I joke and say “It’s my Paxil!”

To relax, sometimes I turn off the phone and answering machine, curl up with a kitty or two (I have eight) on my lap and read or doze with soothing music on. I make sure I stay in communication with God through prayer, worship and Bible studies.

Professor John Darling and Dr Gaetano Finnochiaro

The IBTA Chair with PLGA representative (left) and Joseph B. Fay, Executive Director of the New York-based CBTF (right) at a meeting of the Society for Neuro-Oncology.

BRAIN TUMOURS: THE NEED FOR URGENT ACTION AND FINDING SOLUTIONS

N. PAUL TONNATH
Executive Director, National Brain Tumor Society

I am the Executive Director of the National Brain Tumor Society. I have been in non-profit management since 1991.

I began my non-profit work immediately after divinity school, directing a residential program for persons with major mental illness and continued in the ‘third sector’ because there is much public good that government and industry alone cannot provide.

It is the pressures (of this work) that keep me focused on the real goal. We have to put an end to this devastating disease, then the pressure will subside. I take the most satisfaction in a job well done. At NBTS we are constantly assessing the quality and impact of our work. We feel the urgency of our constituents, the need to help solve the brain tumor problem, and we are fiercely committed to finding solutions.

The biggest challenge of my work in the brain tumour community has been the fragmentation of the community and the many organizations in the field. Diversity is normally a good thing if it does not lead to fragmented focus and duplication of programming. We belong to a relatively small community and there are finite funds and time. Focusing and pooling the finite resources and finding a more unified, thus forceful, voice around the needs of research, support, and public policy is imperative if we are to solve the brain tumor problem quickly. Collaboration is key.

If I think about it in the context of our three programs the first three things on my wish list for brain tumour patients would be: (1) effective therapy for GBM; (2) greater understanding and emphasis on quality of life and (3) a community that can come together quickly to affect change in public policy, both in regards to government and industry.

After relaxation, I am a hopeful motorcyclist. Hopeful because my work schedule and the weather of southern New England conspire to limit my time on the motorcycle.

Treks, therapies and trust…

DR DANNY T M CHAN
Associate Consultant and Deputy Director of CUHK (Chinese University of Hong Kong) Brain Tumor Centre

IBTA: Where did you spend your childhood?
DC: Hong Kong (I am a local Hong Kong, was born, brought up, educated and work here).

IBTA: Did you come from a family environment that had a connection with medicine or research?
DC: No, but my father had a stroke when I was in high school. This encouraged my interest to be a doctor after I had frequent visits to hospital.

IBTA: What attracted you to medicine and, later, to the brain tumour area?
DC: My mentor and professor in neurosurgery gave me a task of reviewing glioma literature and update in glioma treatment during my training. Without any reason I could acknowledge, I felt deeply linked to the glioma patients and their family. I feel honored to be trusted by the patients and families to look after them at the very end of their lives.

IBTA: How do you relax? Do you play music, go for walks, sail a boat? Do you have a hobby?
DC: Jogging, basketball and cooking (eating).

IBTA: How do you cope with the emotional and psychological challenges to you personally arising from your work?
DC: I pray.

The biggest need for urgent action and finding solutions to brain tumours is that there must be an end to the devastation and suffering caused by brain tumours.

N. Paul Tonnath of the National Brain Tumor Society

Dr Danny Chan, participating in the Hong Kong Brain Trekking event for the Walk Around the World for Brain Tumours. Danny was instrumental in establishing this now well-known event in Hong Kong.

IBTA: Do you anticipate any significant breakthroughs in brain tumour therapies in the next ten years? If so, in what area?
DC: Yes and No. Maybe not a cure but more attention and awareness.

I hope we can develop the standard of care and protocol for glioma/brain tumour patients in Hong Kong.
IBTA: Where did you spend your childhood?
TF: Most of my childhood, I was in a small city called "Omachi City" in the Nagano Prefecture. It was really close to "the Japan Alps", which has steep mountains. "Omachi" means "a big town" in Japanese but ironically it was a very small town and has lots of rice fields and apple orchards. During winter time, because it was very cold, we could not do usual physical education at school, instead we did lots of skating in the schoolyard.

IBTA: Did you come from a family environment that had a connection with medicine or research?
TF: My father was a physician in internal medicine. But he was the only one in the medical field in my family. He did his own private clinic and served for local people. Sometimes he needed to go to the next village to take care of a patient. I heard an episode that on his way to the next village over the pass in a heavy snow night, a bear came running in front of the taxi (because of that hospital at that time and under his leadership, I started my research in the neuro-oncology field.

IBTA: Do you anticipate any significant breakthroughs in brain tumour therapies in the next ten years? If so, in what area?
TF: Tough question. Every small step that our colleagues are making throughout the world is important. I do not think one big home-run will solve the problems but "step by step" progresses are more important. As for the areas, "invasion" is one of the most important fields to be faced as for malignant brain tumor therapy.

IBTA: How do you relax? Do you play music, go for walks, sail a boat? Do you have a hobby?
TF: I play trombone in the Orchestra of the Japanese Neurosurgical Society or "the Musica Neurochirurgiana". I also join the student orchestra of the Saitama Medical University sometimes.

IBTA: What attracted you to medicine and, later, to the brain tumour area? What was Dr Fujimaka's mentor, also plays in this orchestra.
TF: Because of my father, I had a feeling that I might become a physician, from my childhood. I thought "probably I will become an internist to succeed my father's clinic". However the situation changed when I was in high school. My mother suddenly died of subarachnoid haemorrhage (SAH). At the time, we did not have a CT scan in Japan. No neurosurgeon was around in the countryside. After I entered medical school, I was interested in many fields, but what attracted me most was neurosurgery, which was in the developmental stage. Later, after I graduated from medical school, I started the residency in neurosurgery. Although the treatment of SAH was interesting to me, I was allocated to an affiliated hospital in a rotation shift, where many brain tumor patients were taken care of. It was so much shocked by the difficulties in the treatment of those patients. Dr Masao Matsutani (2009 World Federation of Neuro Oncology/WFNO President), was chief of that hospital at that time and under his leadership, I started my research in the neuro-oncology field.

IBTA: How do you cope with the emotional and psychological challenges to you personally arising from your work?
TF: I try to face every serious problem without escaping from it. I do my best and if the results were not really good, I feel bad but I try to consider those are one of destinies which I (or that patient) was given (probably from some absolute being).

IBTA: How do you see the future of the brain tumour community? What are the major challenges that the community is facing?
TF: Because from start to finish it constantly poured with heavy rain. This, accompanied by a cold wind, soaked everyone to the skin. However,every single walker completed the course and we are so proud of their efforts on the day...” The walkers raised over GBP £5,000 for brain tumour research.

The Japanese Neurosurgeon bringing hope and music to the neuro-oncology community

Professor Takamitsu Fujimaki
Professor and Chair, Department of Neurosurgery, Saitama Medical University, Japan

Dr Takamitsu Fujimaki with his wife, Wakae, pediatrician and immunologist, after orchestra practice

IBTA - International Brain Tumor Alliance

Flank Boeye was Dr Fujimaka’s mentor, also plays in this orchestra.

FLANK BOEYE
Founder and President, Werkgroep Hersentumoren vzw

werkgroep hersentumoren vzw / study group brain tumours is a patient oriented information and advocacy group registered in Belgium. We also work at the European level and do this together with IBTA, ECPC and EFNA. WG-HT vzw was founded in 2005, with the support of the IBTA. In fact I was seeking documentation about brain tumours since 1997.

I had a high grade brain tumour myself in 1957 (anaplastic astrocytoma / GMB). There was no information available for patients in our language (Dutch) in Belgium, and very little in the Netherlands.

I try to work at my own pace. Sometimes, in crisis situations involving fellow sufferers, this is not possible. It is difficult for a brain tumour patient to cope with tensions, but I try to manage them in a rational way, without getting too much involved myself. After a difficult period rest is mandatory for a few days.

Helping brain tumour patients to get information, a new treatment, comforting them and their families, supporting them in their lives “after the brain tumour” gives me the most satisfaction from my work. Also, negotiating with health authorities to get better conditions of treatment and support.

The biggest challenge of my work in the brain tumour community is that legislation concerning treatment of rare diseases, like brain tumours, is not adapted. Procedures for development and registrations of new therapies were not adapted to specific situations of patients. Getting a greater diversity of treatments is the biggest challenge at this moment.

This could be achieved by creating networks of reference centers with a great range of therapies, adapted to the (genetic) constitution of the patient; (2) palliative treatment if necessary and (3) psychological support for the patients and their families, including support with the re-adaptation and reintegration process for survivors.

To relax, I read a lot of books, and in the summer I go sailing. Our boat is the only means of transport which I can use myself, because it is slow.

IBTA - International Brain Tumor Alliance

The first three items on my wish list for brain tumour patients would be: (1) treatment in reference centres with a great range of therapies, adapted to the (genetic) constitution of the patient; (2) palliative treatment if necessary and (3) psychological support for the patients and their families, including support with the re-adaptation and reintegration process for survivors.

A step closer...Lake Vyrnwy walkers shine, despite heavy rain

With the support of the IBTA, the Study Group Brain Tumours is a patient oriented information and advocacy group registered in Belgium. We also work at the European level and do this together with IBTA, ECPC and EFNA. WGH-HT vzw was founded in 2005, with the support of the IBTA. In fact I was seeking documentation about brain tumours since 1997.

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IBTA - International Brain Tumor Alliance

A performance of the orchestra of the Japanese Neurosurgical Society or "the Musica Neurochirurgiana" at the World Federation of Neuro Oncology Conference in 2000 in Nagasaki. Shown is a skater's reflection, who was Dr Fujimaka's mentor, also plays in this orchestra.

IBTA - International Brain Tumor Alliance

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To relax, I read a lot of books, and in the summer I go sailing. Our boat is the only means of transport which I can use myself, because it is slow.
IBTA: Al, what brought you into the brain tumor information and advocacy area?
AM: It all started when my sister-in-law, Lana, was diagnosed with a glioblastoma multiforme (GBM) in 1992. She had surgery and radiation, and then the first post-radiation MRI showed the tumor had grown [bigger] than it was before the surgery, and we were told it was hopeless. This was before Temodar [Temodal], Avastin and even Gliadel were available. Lana had four young children at the time who really needed their Mommy. When we looked into clinical trials, we were told that there were none for her as her tumor was too large. She was told there was no chance that she would make it to Christmas. The only one that we were told that there were none for was for smaller trials. They said there were no trials that Lana qualified for because the tumor was too large.

I looked online for a brain tumor support group and there were none, only general cancer forums. So, I started the first online support group dedicated to brain tumors on Compuserve and then AOL.

Our members helped me create a database of clinical trials by surveying every major hospital in the USA. We found more than twice as many trials as the NCI had in their database. I published the database online, which was the first brain tumor trials website, and one of the first database-driven websites of any cancer type. The NCI became interested in my website and used it as the model for clinicaltrials.gov. We found many trials that Lana was eligible for. She tried two of them and did much better than expected; she lived eight years, most of which were in good health, which was unheard of back then.

Then, my father was diagnosed with a GBM in 1999. This time we were more prepared, but it was still a horrendous experience. He died in about six months because the tumor progressed so fast that he wasn’t able to complete radiation.

IBTA: The Virtual Trials website must take up a lot of your time. What are you trying to achieve with it?
AM: Yes – it takes a lot more work than you would imagine. I added something to the website daily, and also respond to email and phone calls from the website and our ten online support groups seven days a week. I am trying to do two things with my Foundation.

First, speed up the search for the cure by raising money for brain tumor research and helping direct research. I have had many ideas to improve treatments and found researchers willing to work on them – and then I funded them. I also found researchers with exciting projects who couldn’t find money to do the projects, and I help fund them or find other organizations to fund them. I can’t fund them all, so I (along with the Brad Kaminovsky Foundation and Unlocking Brain Tumors) formed a group called the Grey Ribbon Crusade, which has over 60 brain tumor foundations working together to help fund research projects.

We also track the treatments being done and the outcomes, in our Brain Tumor Virtual Trial, so we can get an early warning if a new treatment or combination of treatments are working or not. The second thing is to help families deal with the diagnosis of a brain tumor. This is one of the most devastating things that can happen to a family. Immediately, the entire family goes into shock when they understand what a diagnosis of GBM or DIPG (diffuse intrinsic pontine glioma) means. Then they are called upon to quickly make the biggest decisions of their lives - which doctors to use; which trials to enter - without enough information to make a rational decision, without understanding the terminology and while being in shock.

I see a lot of people who find too many options and waste valuable time trying to find the answers – so much time that they lose the battle without having made a decision.

My aim with the website is to allow people to become educated about the disease so they better understand the choices out there, and so that they can better understand what the doctors are talking about, and therefore make more educated choices. We help people – both through the support groups and individually, go through the choices they have and help them choose.

We also had success with advocacy issues such as helping get Temodar and Avastin approved by the FDA, and getting Medicare to pay for Temodar and Gliadel.

IBTA: Give us some background on the virtualtrials.com website.
AM: The website started out as the file library of our Compuserve cancer forum in 1993, which had a file listing all available clinical trials for brain tumors as well as important articles and educational material. When the web was launched with Netscape the next year, I started experimenting with the web and moved the library to a website and added an online forum. We changed from using a text file for the trial listings to using a database-driven format which was easily searchable and sortable.

For example, you could now list them by state, or list only a certain phase or type of trial, or find all trials by a particular doctor or hospital, or trials that allowed or didn’t allow prior surgery, radiation or chemo.

Back then domain names were expensive, so I piggybacked off of the website of one of my friends. Then in 1996 I took the plunge and registered the domain name virtualtrials.com. The name came from our Brain Tumor Virtual trial project. We used .com instead of .org because this was before we became a non-profit organization, which we did on March 15, 1997. At that point we added the domain name virtualtrials.org which points to the same website as virtualtrials.com, but we had so many links in publications and on the web that pointed to the .com version that we just kept it as the main domain name.

The website has grown every day in size, and now is made up of over 13,000 files, taking over 8 gigabytes of space, not including the 20 gigabytes of video in our video library. We use an MS Sql server database that now has over 600 megabytes of data.

In the last year, we had 2.6 million visitors from 203 countries (36,000 visitors from Australiat), generating 26 million hits.

We have some exciting plans for the future of the website and welcome suggestions and submissions of articles or videos!

IBTA: What is your background?
AM: There were three factors in my background that influenced my ability to run the Musella Foundation.

I still work part time as a podiatrist in New York. The first two years of podiatric medical school are the same as the first two years of medical school. Some of the courses we studied included pharmacology, neuroanatomy, surgery, radiation, immunology, biochemistry, and research methods. I even dissected a few human brains. I also read many brain tumor articles and books, and attend brain tumor conferences to keep up with changes in the field.

I was a computer geek in high school and college and worked my way through college doing research on artificial hips at a medical school. I designed the computer software and testing apparatus used to develop a new type of hip replacement. I also did the programming for the

IBTA: What is your background?
AM: Ben Williams, PhD, is a 14 year survivor of a GBM, being diagnosed 1995. He has written a book about his journey titled: Surviving Terminal Cancer: Clinical Trials, Drug Cocktails, and Other Treatments Your Oncologist Won’t Tell You About. The book can be purchased online via Amazon.com and a regularly updated report by Ben Williams on GBM treatments is available here: http://virtualtrials.com/williams.cfm

When I began researching treatment options on my own, it quickly became clear that the best way to disseminate that information was via Al’s website, rather than develop a competing website. Part of Al’s value comes from being his very well-known, and widely respected, in the neuro-oncology community, which allows him access to a great deal of "insider information" that is not available from journals and conference proceedings.

Ben Williams
first version of the orthopedic index – which became the model for the online version of Medline. I got into creating websites back when Netscape first came out – around the same time Lana was diagnosed. The first major website I created was for brain tumors which later became virtualtrials.com. Since then, I formed a company to create websites and have created a few other major websites. I wrote 100% of the code that runs virtualtrials.com. (I did have help with the graphics).

And finally, my experience of going through this ordeal multiple times enabled me to see the problems and concerns that pop up and how best to handle them. Aside from Lana and concerns that pop up and how best to handle them. Aside from Lana and...
Paediatric researcher is in for the long haul - marathons and persistence

**DR ERIC BOUFFET**
Director, Brain Tumour Programme, The Hospital for Sick Children, Toronto, Canada

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

**EB:** In France, more precisely in Metz, a middle size town in the eastern part of France.

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

**EB:** Yes and no. My dad was working in the army. My mom was a nurse, but she stopped working ten years before I was born. Having said that, she was very proud when I decided to become a physician.

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

**EB:** When I was 17, I got a grant and travelled to Africa (Ivory Coast). There, I pushed the door of a dispensary with medicine or research? IBTA: Did you come from a family environment that had a connection with medicine or research?

**EB:** I went running (60 km/week, one or 2 marathons per year), I play guitar and I like reading. But above all, time with my family.

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

**EB:** I have a great team, fantastic colleagues, and we talk a lot. We have weekly psychosocial rounds with the team. My wife is a great support as well. And running is a great way to put things in order in my brain!

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

**EB:** There is a gap between dreams and expectations. My dream (and we are fighting hard to make this happen) is to see a breakthrough in the outcome of children with diffuse brainstem gliomas. But we can certainly expect small molecules therapies in the next ten years. If so, in what turbins.

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

**HW:** My Dad bought a farm 60 miles from any civilization - or hospital. My original plan when I enrolled in medical school was to be a part-time country GP and run the farm. I really enjoyed medical training, and then decided to do oncology. Much to my disappointment, Dad sold the farm. There was no such thing as neuro-oncology when I trained. Patients were simply discharged post-op or referred to radiotherapy. We then got an enthusiastic group of young neurosurgeons who had just returned from the US who started to ask for consults. Completely out of my depth, I enrolled and went to a SNO (Society for Neuro-Oncology) meeting in San Francisco in the late 1990s. I must have looked very lost. I must have been one of the only “foreigners” there, and somehow got “adopted” by Skip Grossman, Jan Buckner and Greg Cairncross (three eminent neuro-oncology specialists).

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

**HW:** Canberra. “My parents moved there when I was three. Dad was in the Air Force so I was there until I moved to Sydney University at 18.

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

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**HW:** I love to garden and have been a very keen fisherman in my time.

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

**HW:** You just have to set limits. I doubt I will ever see the day when we can “cure” high grade brain tumours and I see my role as making the very best of what we currently have (not to say I don’t always hope for miracles). It is rare however that you can’t do something in help. Knowing that all that can be done has been done, no matter how big or small, makes every case worthwhile. The frustrations of limited resources and red tape can really make me boil from time to time and I don’t think I would cope as well if I wasn’t involved in research - trying to understand why and how best to treat- it (brain tumours) just all goes so slowly.

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

**HW:** I think the next ten years will be very exciting for neuro-oncology. The technological advances that are infiltrating the labs at the moment are making everything so much quicker. Brain tumours have suddenly gone from “not interested” to a very hot topic with the big pharma companies (not to say about 20 years too late). I think we can expect very big changes in the near future. I see my role as trying to keep everyone well till they land in Australia, but unfortunately that is a big call at present.

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

**HW:** I love to garden and have been a very keen fisherman in my time.

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

**HW:** I went running (60 km/week, one or 2 marathons per year), I play guitar and I like reading. But above all, time with my family.

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

**HW:** I have a great team, fantastic colleagues, and we talk a lot. We have weekly psychosocial rounds with the team. My wife is a great support as well. And running is a great way to put things in order in my brain!
I am very interested in those patients who were diagnosed with primary brain tumour centre in Canada. I am also the current Chair of The Canadian Alliance of Brain Tumour Organizations (CABTO), which is an alliance of volunteer organizations, dedicated to enhancing the quality of life of brain tumour patients and families. CABTO is a proud member of the IBTA.

IBTA: What long have you been doing that or similar work?
MD: I have held the position of Coordinator in The Pencer Centre for the past 12 years. Prior to that, I worked in the neurosurgical intensive care unit as a staff nurse at St. Michael’s Hospital in Toronto for 15 years.

IBTA: What led you to become involved in that way?
MD: While working in the neurosurgical ICU (Intensive Care Unit), I became very interested in those patients who were diagnosed with primary brain tumours. The challenges they face, and the resilience with which they address them is inspiring. When The Pencer Centre was being developed, and the therapist who became a patient

REVERSING ROLES:
The therapist who became a patient

ERIC GALVEZ
Brain tumour survivor (United States)

I was diagnosed with a golfball sized meningioma between the brain stem and cerebellum in 2005. I had surgery, radiation, and months of physical rehabilitation.

I was working as a physical therapist in San Diego, California before my surgery. I was left with significant physical impairments after surgery and radiation to treat this "non-malignant" brain tumor. I am unable to return to my career as a physical therapist. I became someone I was trained to help. I am currently unable to return to my previous work, but I am finding ways to keep myself busy. In 2007, I wrote a book about my experiences with a young active healthcare professional turned brain tumor patient. It is called "Reversal: When A Therapist Becomes A Patient". I am also starting a charitable organization, mAss Kickers Foundation (mKF... www.mAssKickers.org). We look to empower newly diagnosed tumor/cancer patients with "the K.U.R" (Knowledge, Unity, and Research) so that they can live their life changing event regardless if it is malignant or non-malignant. Try to keep your composure when talking to doctors. It might be a good idea to bring another level head with you to appointments to take notes.

I think everyone needs to be their own advocate - researching, understanding health decisions/risks/options. I was never passive in my treatment regimen. I do not feel like anything could have been improved. I felt like I was in control. The first three things on my wish list in relation to this disease are: (1) that I wish I had found more people like me when I was first diagnosed. It was a very intimidating thing to deal with. (2) that I wish I had known ALL my treatment options. (3) that I wish I had known someone who I could turn to who knew the answers to my questions. I relax by reading a good book, going to the beach, or going out with my friends in San Diego.

A step closer... under 12s stern ahead
Tim Erickson, Secretary of the Victorian Racewalking Club (Australia) reported that members raised AUD $650 for the Royal Melbourne Hospital Neuroscience Foundation at the annual Australian Postal Challenge event on 11 July, 2009, a day on which the wind was "gale force" and cold. The 72 club members contributed a total of 372 km to the World Walk target. Reproduced below is a photo of competitors in the under 12 years event.

A step closer... Bryon's 3.3 event
Michelle Latvis from Bryon's First Annual 3.3 mile Run/Walk/Stroll in Bristol, Connecticut (United States) wrote to us to say that the event was a great success with 332 participants completing 3.3 miles each for a grand total of 1026 miles. Why 3.3 miles? Because little Bryon Schiffies is three years old and the event was in his honour. Bryon was diagnosed with a brain tumour in January 2009.
MENINGIOMA UK

ELLA PYBUS
ICoordinator and Director of Meningioma UK, Brain Tumour UK Support Organiser

I am the Coordinator and Director of Meningioma UK. I’m also Brain Tumour Support Organiser for Brain Tumour UK and Meningioma UK in the Eastern Counties.

I’ve been involved in this work since 1999. After Caroline Batt (another meningioma patient) and I met on a US website, we decided to start a national support group for meningioma patients like ourselves in the UK.

After I was diagnosed with an inoperable brain tumour in the mid-nineties, my GP told me I was only the second brain tumour patient she had seen in 23 years! Then I found there was little or no information for meningioma patients in the UK.

As patients we need support and we need information we can understand, so Meningioma UK was born out of necessity.

I don’t cope as well as I would like (with the pressures that develop in this work), but there is solace in helping someone understand what’s happening to them, and to see them recovering their self-confidence and self-esteem after the stuff has been knocked out of them by a brain tumour.

What gives me the most satisfaction from my work? Knowing that other people, whether young or old, get the help and information they need so they can feel confident when they talk with their doctors. The biggest challenge of my work in the brain tumour community has been the uphill struggle keeping Meningioma UK afloat without money.

I’ve been involved in this work since (2) world-wide neurology treatment and oncology clinical nurse specialist; and (3) world-wide neurology treatment and care for all CNS tumour patients.

I find it hard to switch off, but I’m lucky that I’m a reader so I can always escape between the covers of a good detective story. My problem is that great writers like Donna Leon, Val Mcdermid, and Ian Rankin just don’t write them fast enough!

The privilege of caring for brain tumour patients

DR SUSAN CHANG
Director of Neuro-Oncology, University of California, San Francisco, United States and Past President, Society for Neuro-Oncology (SNO)

IBTA: Where did you spend your childhood?
SC: I was born in Arima, a very small town in Trinidad and Tobago, the most southerly islands in the Caribbean. It was a very stress free childhood with memories of tree climbing, ocean swimming and tropical weather. I moved to Vancouver, British Columbia, Canada at the age of 17 and pursued my medical training in Canada.

IBTA: The first snowfall was quite a shock.
SC: Did you come from a family environment that had a connection with medicine or research?
IBTA: One of my uncles was a laboratory haematologist however when I was growing up, he trained and lived in England and I was not familiar with his work. There were no others in the family who were in the field of medicine. I asked for a medical kit for Christmas at age eight and started volunteering in the hospital at age eleven, mainly visiting and reading to children in the pediatric ward where I became familiar with the medical environment. My goal of being a doctor was formed at this early stage and my parents provided encouragement and support.

IBTA: What attracted you to medicine and, later, to the brain tumour area?
SC: The chance to help patients personalize the approach to their care and the challenge of life long learning were what attracted me to the field. I found medical oncology particularly interesting and in 1991 I had the opportunity to complete an elective in Neuro-Oncology at UCSF during the last three months of my oncology fellowship in preparation for my first academic career position as an independent physician. Several aspects of caring for brain tumor patients made me realize that this was how I wanted to spend my career. The privilege to be able to care for this group of cancer patients and their families from the time of their diagnosis throughout the entire span of their illness was critical in terms of continuity of care. Interacting with dedicated physicians who were in various disciplines in medicine was very invigorating and it was exciting to see the advances in the scientific discoveries in neuroscience that could eventually translate to improved outcome for our patients. All these remain true 20 years later.

IBTA: How do you relax? Do you play music, go for walks, sail a boat? Do you have a hobby?
SC: Spending as much time outside of a demanding work schedule with my family is a priority for me. I love to travel, read and hike. I enjoy the outdoors and luckily I live on the border of a wonderful national park so daily walks among the hills is particularly rejuvenating.

IBTA: Do you anticipate any significant breakthroughs in brain tumour therapies in the next ten years? If so, in what area?
SC: I am very hopeful that there will be significant breakthroughs in brain tumour treatments through continued understanding of gliomagenesis and the development of new treatments targeted to various signalling pathways in the tumor. Areas include an improved knowledge of the relevance of tumour initiating cells, neural stem cells and mechanisms of resistance to treatments. Individualization of the care of patients remains an important goal.
**Childhood Brain Tumours**

International call for greater attention to be given to childhood brain tumours

Joint Statement by the UICC and the IBTA – February 2009

The International Union Against Cancer (UICC) and the International Brain Tumour Alliance (IBTA) issued a joint statement to coincide with International Childhood Cancer Day (15 February, 2009) drawing attention to the fact that in a number of countries* brain tumours are now the greatest cause of childhood cancer mortality in the age group 0-14.

While today there are many childhood cancer survivors because of improvements in treatments, brain tumours are lagging behind, principally because their causes are currently unknown, they cannot be detected early.

IBTA Chair Denis Strangman said that worldwide approximately 200,000 people each year develop a malignant primary brain tumour for which there is no cure and very little in the way of effective treatments.

“There is a real need to promote a wider public understanding of the challenges faced by brain tumour patients, their families and their caregivers,” says Isabel Mortara, Executive Director of the UICC. Both organisations called for a greater effort to be made in combating brain tumours, particularly childhood brain tumours. They welcomed signs of increased activity, including moves in the USA Congress to establish a Childhood Brain Tumor Prevention Network and the decision of the European Rarecare Project (a European Commission-funded initiative) to construct a table of rare cancers which includes brain tumours.

In support of the call for greater attention to be given to brain tumours, Professor Larry Kun, Chair of the US Pediatric Brain Tumor Consortium, described childhood brain tumors as “perhaps the most vexing area of pediatric oncology”. Mr Mike Traynor**, who is President of the Pediatric Brain Tumor Foundation in the US, the world’s largest non-governmental funder of pediatric brain tumor research, said that “Childhood brain tumours are one of the most underserved areas of cancer research which requires the philanthropic community to provide significant funds to bring an understanding of the disease and to save the children afflicted with brain tumours.”

Professor Martin van den Bent from the Daniel den Hoed Cancer Center/Erasmus University Hospital in the Netherlands and Chair of the EORTC Brain Tumor Group, said: “These children not only suffer from having a malignant disease. They also suffer from the consequences of having a severe neurological illness with many behavioural and cognitive problems, even if treatment has been successful. Because of these, childhood brain tumour patients need to become a top priority in cancer research.”

Professor David Walker of Nottingham (UK) said that enhancing the timeliness of diagnosis in children could reduce visual impairment “which is the most damaging neurological consequence of delayed diagnosis that is so common across the world.”

Professor Victor Levin of the MD Anderson Cancer Center in Texas, said that the major problem “is that there are no cure and very little in the way of effective treatments for leukaemia although this has happened in some instances, but because of more effective treatments for leukaemia and insignificant improvements in the treatment of brain tumours.


Legislation for the proposed US National Childhood Brain Tumor Prevention Network has been introduced by US Senators Charles E. Schumer (D-NY), David Vitter (R- LA) and Congresswoman Barbara Lee (D-CA).

Further information on the EU rare cancers project can be found at: www.rarecare.eu/aims/aims.asp •

A step closer… mountain top marvel

William Cruz Abbott from the Philippines is a gymnastics acrobats on grade two brain tumour survivor. Recently he climbed Mt. Pulag in Benguet which is the second highest mountain in the Philippines (9,586 feet above sea level) with the assistance of his neurosurgeon and a lot of friends. Will was the first case of awake craniotomy at the Medical City (TMC) in Pasig City Metro Manila. You can see a programme about Will on YouTube here: http://www.youtube.com/watch?v=VhohSz4rnHE. Will, his neurosurgeon and friends are donating 249 kms to the Walk Around the World for Brain Tumours. Will is also involved in a project which will benefit neuro-patients called the “Garden of Hope” (“Hardin ng Pag-asa”). See this webpage for the background to this inspiring project: http://wilsumati.multiply.com/photos/album/7#.

A step closer… Big Wight Matter spotted off English coast

Helen Bulbeck, Director of Brainstrust (United Kingdom - the Meg Jones brain cancer charity), described their 2009 Big Wight Matter, Walk on the Isle of Wight: “We had a wonderful weekend, not least because of the weather! We managed to walk a total of 642 miles for IBTA over the weekend. That was by a group of about 40 people. We have said that they are bringing friends and family next year because it was such a great event! So this week we are already planning next year’s! No doubt soon we will earn enough miles for Big Wight Matter to walk around the world by itself!”
Determinations and dedication: caring for brain tumor patients

PROFESSOR MARTIN VAN DEN BENT
Professor in Neuro-Oncology, Head, Neuro-Oncology Unit, Daniel den Hoed Cancer Center Erasmus University Medical Center, Rotterdam, The Netherlands

IBTA: Where did you spend your childhood?

MVDB: Badhoevedorp, a small village adjacent to Amsterdam.

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

MVDB: No, neither of my parents had anything to do with medicine. Yet each of their three children became doctors.

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

MVDB: Giving care to people attracted me, and what attracted me to neuro-oncology is that in this area, one is taking care on a daily basis of real health problems.

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

MVDB: At the weekend, I do some cooking - eastern style, including sushi and curries, which is not always relaxing though...

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

MVDB: At some point in time the knowledge on the molecular background of brain tumors will translate into better drugs. Although this may come in small steps, in particular in small molecularly defined subsets of tumors.

A CAREER IN “THE GREATEST SPECIALITY IN THE WORLD”

DR CHARLIE TEO
Neurosurgeon
Founder, Cure for Life, Australia

IBTA: Where did you spend your childhood?

CT: I was born in Sydney, Australia and spent my early childhood at home before going to boarding school at the age of nine.

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

CT: My father, although not having a medical background, was an obstetrician/gynaecologist. My mother, who essentially raised me, was a nurse.

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

CT: After initially wanting to be a mechanic, and commencing an apprenticeship, I didn’t like the lack of human contact and knew that I would be happier helping others. I loved medicine from the start and after every rotation through both surgical and medical specialties I thought that I had found my calling! The only specialty that scared me was neurosurgery and I would use any excuse to avoid contact with neurosurgical patients.

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

CT: My family is my emotional ballast. I also support an orphanage in Cambodia to which I travel and spend time helping the kids. It is a far cry from neurosurgery and allows me time to clear my head and get things in perspective.

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

CT: Absolutely. If you had asked me this ten years ago I would have been quite nihilistic. However, with the groundbreaking work that has been done by scientists such as Dr Kerrie McDonald, at the Lowy Cancer Center, who has identified genes that are instrumental in transforming low grade gliomas into high grade gliomas, I honestly believe we will be able to control malignant brain tumors in the next ten years.

Dr Charlie Teo meets the Dalai Lama.

Dr Teo is an enthusiastic motor bike rider but he makes sure he wears a safety helmet.

IBTA: Do you have a hobby?

CT: I am a very physical person and must be active whenever I have spare time. I like walking my dogs, exercising, kayaking, swimming, motorcycle riding and hiking. Of course, all that exercise results in a healthy appetite, which I satisfy by eating out occasionally at good quality restaurants. When my children were young, I was able to encourage them to join me in all my activities. Now that they are teenagers, it’s not so easy.

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Atitute: Where did you spend your childhood?

Dr Teo climbs a snow-covered mountain in Ecuador

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Founder, Cure for Life, Australia

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Founding Trustees, Samantha Dickson Brain Tumour Trust (SDBTT)

ANGELA AND NEIL DICKSON

INSPIRING LEGACY

SAMANTHA’S

ANGELA AND NEIL DICKSON

NNeil is Chairman of the Samantha Dickson Brain Tumour Trust, and I (Angela) am a Trustee. Both of us are Founding Trustees and we work as Volunteers. Neil is a member of NCRI (National Cancer Research Institute) brain tumour clinical trials group. We founded the charity in 1997, and have since raised over £8 million and have become the largest funder of brain tumour research in the United Kingdom.

We lost our 16 year old daughter Samantha to a brain tumour in October 1996. Despite brain tumours being the second most common childhood cancer and killing more people under 40 than any other cancer, we were amazed at the lack of research and support for brain tumours in the United Kingdom. This led us to establish the first charity dedicated to brain tumours in the UK, with an impressive Scientific and Medical Advisory Board, along with over 250 experts in the field of neuro-oncology throughout the world who help review our research projects. We wanted to be sure we funded the top projects available, leading to increased survival rates.

We are able to overcome the pressures that develop in this work because since we have started the charity we have met thousands of children and adults diagnosed with a brain tumour. Their courage and dignity, despite being affected by this dreadful illness, continues to amaze us and is an ongoing inspiration.

What gives us the most satisfaction from our work? The fact that we really are making a difference. In the last two years a number of our research projects are now translating from the laboratory to the clinic and are creating new clinical treatments and improved diagnosis for children and adults with a brain tumour. With our developing Patient Support Service, we are also providing information and support to hundreds of patients as well as their families and carers all over the country. The letters and praise we receive from so many people we have helped over the years has been an incredible boost to us.

The biggest challenge in our work in the brain tumour community is the continuing struggle to increase public and government awareness concerning this dreadful disease.

The first three items on our wish list for brain tumour patients would be: improved treatment and increased survivability; increase support and raise our research funding from £1 million a year, to £5 million; increase national awareness and Government support for brain tumours.

Despite the demands of a growing charity, and a busy family life, we find time to travel, work in the garden (Neil has his own small vineyard!), sometimes swim and enjoy walking when we can (although the latter is usually on holiday).•

A proud day - Angela and Neil at son William’s university graduation.

Dr Sherry Fox

Director, Cullather Brain Tumour Quality of Life Center, United States

IBTA: What is your current position(s) in the brain tumour movement?

SF: I am the Director of a very unique brain tumor center which is dedicated solely to addressing the quality of life issues faced by brain tumor patients of any age, with any type of diagnosis and across the entire illness trajectory.

IBTA: How long have you been doing that or similar work?

SF: I have been a neuroscience nurse for 32 years but focused heavily on work with brain tumor patients for the past 18 years. I have directed the Cullather Center for the past four years.

IBTA: What led you to become involved in that way?

SF: I believe I have a calling to serve the underserved, and brain tumor patients have been underserved. I am a problem solver. I love puzzles and so working with these patients gives me a very unique opportunity to look for creative solutions to difficult problems. I became the Director of the Cullather Center because of a relationship I formed with the family of a young man that I cared for who died of a GBM.

IBTA: What is your current position(s) in the brain tumour movement?

SF: I am answering my calling is also the biggest challenge of my work in the brain tumour community?

IBTA: What is your current position(s) in the brain tumour movement?

SF: Finding health care professionals, particularly psychiatrists, family physicians, who understand the unique needs of patients with the brain injury that comes from having a brain tumor. The most difficult symptoms to manage are the psycho-behavioral symptoms and not having access to physicians who can manage these symptoms is frustrating.

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

SF: I am an antique freak. I love to spend long days poking around in antique shops and looking for new and creative ways to use vintage items.

IBTA: What would be the first three items on your wish list for brain tumour patients?

SF: (1) a cure; (2) the same level of funding for research and advocacy that is received by breast cancer patients; and (3) easily accessed help that promises the best quality of life they can have every single day.

For a not-for-profit organisation, the IBTA has an unusual attitude towards development.

We don’t wish to receive any funds from the over 180 organisations who have supported 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, as a completely voluntary organisation with no paid staff 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: chair@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 but do not neglect your local or national brain tumour support groups.
Brain Tumour
That’s when I fell in love with helping brain tumor patients for recurrence. I worked with Dr. Philip Gutin in the clinic with physicians to whom I then following them on the wards and theatre, while the patients were awake; doing the surgery in the operating that I was the Stereotaxic Head Nurse for eight years, then moved to in Neuro-Radiology at the University adults in my family are teachers (I use nursing and, later, to the brain tumour

IBTA: Where did you spend your childhood?
SL: Toronto, Ontario in Canada

IBTA: Did you come from a family environment that had a connection with medicine or research?
SL: No. My father was a Physics/Chemistry Professor at the University of Toronto; then Queens University in Kingston, Ontario. My mother was a homemaker turned teacher.

IBTA: What attracted you to the field of nursing and, later, to the brain tumour area?
SL: I have no idea. I have always wanted to be a nurse. All working adults in my family are teachers (I use teaching skills in my nursing too) I was in Neuro-Radiology at the University of California at San Francisco (UCSF) for eight years, then moved to neurosurgery. It was in neurosurgery that I was the Stereotaxic Head Nurse doing the surgery in the operating theatre, while the patients were awake; then following them on the wards and in the clinic with physicians to whom I reported. I worked with Dr. Philip Gutin implanting iodine radioactive seeds in brain tumor patients for recurrence. That’s when I fell in love with helping brain tumour patients and carers.

IBTA: How do you relax? Do you play music, go for walks, sail a boat? Do you have a hobby?
SL: I love almost all kinds of music from country to classical and have it on all the time in the car and at home, I repair antique clocks (movements) as a hobby; garden a little; hug my beagle; work out in the gym; spend time with friends, now that I’m retired from nursing. I also volunteer my time at the National Brain Tumor Society (NBTS) weekly. I am learning about fine porcelain; go to medical and other lectures and enjoy antiquing.

IBTA: Do you cope with the emotional and psychological challenges to you personally arising from your work?
SL: There are times when I ’need to get away’ from all aspects of healthcare. If I’m not ‘going on a vacation’ I just stop reaching out to people for a week usually and get re-charged; ready to help again if needed.

IBTA: Do you anticipate any significant breakthroughs in brain tumour therapies in the next ten years? If so, in what area?
SL: I do. I am very hopeful. I feel the genomic and proteonomic work underway in research will help us better predict and define what’s the best therapy for our patients. In forty years, this is very exciting. A typical example is the 1P/19Q work and Tenodar as an oral agent keeping our patients alive for so much longer.

IBTA: What is the greatest challenge of being a specialist neuro oncology nurse? What is the greatest pleasure?
SL: I’ve been so fortunate to be at the UCSF Center of Excellence in brain tumor work for over 40 years. I think for me the challenge is keeping up with the research and new advances as this has become so complex. I have to guard against becoming so involved with my patients and families that I lose my perspective and objectivity. The greatest pleasure for me is to be there for people as long as I’m needed; to offer whatever assistance I can and to learn from those people I serve, allowing me to share what I learn with others.

IBTA: What is your current position(s) in brain tumour movement?

IBTA: How long have you been doing that or similar work?
RC: About 15 years.

IBTA: What led you to become involved in the brain tumour movement?
RC: From the first time I worked with brain tumour patients and their families I was moved by the enormous challenges they faced and wanted to help them.

IBTA: How do you cope with the pressures that develop in this work?
RC: Live life to the fullest - so many things to be grateful for: meaningful relationships, travel, the natural beauty of British Columbia and other places.

IBTA: What gives you the most satisfaction from your work?
RC: The feeling that I make a difference to someone who is struggling, feels alone, is suffering.

IBTA: What has been the biggest challenge of your work in the brain tumour community?
RC: Losing people I become close to; seeing people suffer.

IBTA: How do you relax? Do you have a hobby or a sport with which you are involved?
RC: Cycling, hiking, running, travelling, drawing, reading, cooking, friends, family.

IBTA: What would be the first three items on your wish list for brain tumour patients?
RC: Same as for us all - discover who you love, what you value, why you're here.
"Keep strong-willed and optimistic"

By Eve Lee – Singapore

I have a Malignant brain tumor (anaplastic oligoastrocytoma), located in the left cerebellum, which was diagnosed on 20 December 2006. It has affected my life, in so far as I need to have more rest, I am unable to do office work and my memory is not as good as it once was. I am no longer in the paid workforce.

I receive support from my family, relatives, close friends, my Church, and my brother & sister. I have made contact with other brain tumor patients through the Brain Tumor Support Group at the Singapore National Neuroscience Institute. It is helpful for a patient’s attitude towards life to keep strong-willed and optimistic.

In relation to this disease and myself the three things I wish for are: A. The love and encouragement from my family, B. That my children will be independent and have a good job, and C. That I am allowed to travel to many countries by myself.

My advice to other patients is to: eat healthy foods, follow instructions from the Doctor and nurses, and make the Doctor aware if you have any pains in your body.

I relax by reading, listening to music, going for a morning walk, and spending time with my children. I also enjoy travelling and cooking.

My favourite pastimes are reading, listening to music, go for walks, sail a boat? Do you have a hobby?

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

PATIENCE AND A POSITIVE OUTLOOK

DR RAKESH JALALI
Associate Professor of Radiation Oncology, Tata Memorial Hospital, and General Secretary, Indian Society of NeuroOncology.

IBTA: Where did you spend your childhood?

RJ: I spent my childhood in the scenic environs of Kashmir, which is one of the most beautiful places on Earth.

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

RJ: Not really, although my father was an academician in agricultural sciences.

IBTA: What attracted you to medicine and, later, to the brain tumour area?

RJ: I have to say I joined medicine a bit reluctantly initially. I soon discovered however what a fascinating field it is. I do feel strongly that it is one of the most interesting and challenging branches based on applied science and at the same time, offers you opportunities of management, interpersonal skills and communication, mentorship, academia, charity work, etc. Personally I enjoy talking and interacting a great deal with my patients, association with students and supporting people with brain tumours to the hilt. What is amazing amidst all of this (and technological advances), is that practising medicine (at least the clinical side) is still to a large extent, an art.

I am devoted to neuro-oncology for the wide variety of histological/clinical types of tumours that we see and some of most challenging ones in any form of oncology, as well as from cure and quality of life perspectives. I am hopeful of and committed to dispelling nihilism that the branch appears to be associated with.

IBTA: How do you relax? Do you play

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

RJ: I think so. Improved insight and understanding of the biology of many of these tumours and employing appropriate strategies to overcome them are already in the pipeline. There is likely to be a more cohesive global effort to maximise research efforts in a relatively short time as well.

LESLEY GLOVER

Brain Tumour Support Group

On 28 June 2009, 528 miles was covered in a fund raising walk for Brain Tumour UK. The route covered 32 miles of Dorset’s Jurassic Coast from Weymouth to Worth Matravers.
The aviator, antiangiogenesis and Avastin - an interview with solo practitioner Dr Virginia Stark-Vance

DR VIRGINIA STARK-VANCE

Solo practitioner in Dallas and Forth Worth, Texas, USA

IBTA: Where did you spend your childhood?

VSV: I spent my childhood in Oklahoma City until the age of eight, when my father moved us to the Texas Panhandle, where he worked in the oil business. My hometown, Perryton, is in far north Texas, a town of about 7,000 people. My mother still lives there today.

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

VSV: As a teenager we lived next door to a primary care doctor, and I used to baby-sit for his small children. I was fascinated by his shelves of medicine, and at the age of fifteen my family has several physicians who trained at the University of Oklahoma, and after graduation from high school I attended the University of Oklahoma on a scholarship.

Unfortunately, with an older brother and sister also in college, it was very difficult for my family to have us all in college at the same time. After my first year, I joined the Air Force, which at that time had an outstanding tuition assistance program.

For the next four years, I worked at my Air Force job in the afternoon, attended night school at the local college, and took flying lessons in the morning! I was then transferred to Germany, which made continuing college a bit more challenging. However, I worked with some Air Force physicians who were very encouraging of my goal to return to school and become a physician.

When I returned to the United States in 1978, I was married with two small children. To care for them, I went to the University of Oklahoma and night school, to finish my degree as soon as possible. Of course, convincing the medical school admissions committee that I could do my coursework while caring for two pre-schoolers was not easy!

I am very grateful that my college professors back at Oklahoma University gave me great recommendations. Were it not for them, I am sure I would have been denied the opportunity to attend medical school at all.

IBTA: What attracted you to medicine and, later, to the brain tumour area?

VSV: While in medical school, I was the third year student, I saw my very first MRI of a patient with a glioblastoma. It made a tremendous impression on me at the time - I can still remember how it seemed to invade the entire left hemisphere. I was convinced I wanted to become a neurosurgeon.

But at that time something truly remarkable happened - I was chosen to take part in a one-year research program at the National Institutes of Health (NIH) in the first group of Howard Hughes Medical Institute Research Scholars. I worked in the human gene therapy lab, with W. French Anderson, who is an Oklahoma native. That experience led me to pursue oncology research, and after my residency at Georgetown University Hospital in Washington D.C., I returned to NIH.

During that time, I worked with the National Cancer Institute and National Eye Institute to develop a new treatment for ocular and central nervous system lymphoma. I think the success in treating - and curing - central nervous system lymphoma has made me much more optimistic that other brain tumors could also be successfully treated.

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

VSV: I moved back to Texas in 1996 and have been in solo practice for the last ten years, with offices in Fort Worth and Dallas. Two offices 50 miles apart - with hospital rounds in both cities 7 days a week - doesn't leave me much “spare” time. I do gardening, painting, and stained glass when I have some free hours on the weekend.

Because I spend so much time in my car, I listen to audio books every day. One of my favorites is “Pilgrim’s Progress,” read by Max McLean. My “favorite” activity is drinking coffee in bed Saturday morning while reading the Bible.

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

VSV: I read the Bible every day, and I find so much comfort and hope in its pages. I have a deep faith that God has given us all tasks to serve Him, and I am constantly asking, "Am I doing the right thing with this patient?" I want Him to guide every decision I make. Of course I am not perfect, and I lose my temper at times, particularly when insurance denies something I think one of my patients needs! But I try to leave everything in His hands.

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

VSV: I am confident that there will be more significant breakthroughs in brain tumor therapy in the future, in all areas. That includes targeted therapies, vaccines, and chemotherapy, as well as advances in neurosurgery. I tell my patients, "It’s my job to keep you alive until the cure comes along!"

We are learning so much about how cancers develop and their molecular makeup; this understanding will eventually lead to interventions that exploit the unique abnormalities in tumors and spare other normal tissues. I am concerned, however, that designing therapy based on a patient’s tumor’s genetic profile will be met with resistance from insurance companies who deny anything not “standard.”

I do not see any provisions in the new healthcare legislation that will allow patients to be treated based on their tumor’s unique characteristics; this could be a problem for brain tumor patients.

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

VSV: I love to tell the story about how Avastin was “discarded” to work in malignant glioma!

One of my patients had a glioblastoma that had been slowly growing despite her therapy. I mentioned to her husband Les that I anticipated that Dorothy may respond better to a different drug. At that time, Avastin had just been approved for use in colon cancer. Les said, "Why not Avastin?"

I read everything I could find about Avastin and even called the drug manufacturer but did not find any data at all in brain tumor patients. One of the neurosurgeons I knew at NIH had worked extensively with vascular endothelial growth factor, believing it to be a key in tumor development. Based on what I knew of his work, and what I knew about Avastin (not much), Les and Dorothy and I agreed to try it for one month.

I was very concerned that giving Avastin could cause a stroke or a haemorrhage, and Dorothy was admitted to the hospital to allow close observation. To our surprise, Dorothy actually noted some improvement in her strength within a few days of her first dose of Avastin. Also, her MRI showed a dramatic improvement compared to her previous scans - much so that the neuroradiologist called to ask about what she had received.

I was very cautious at first about treating other patients with Avastin, but there were many patients willing to try somethings new, even knowing there were risks involved. I began a small study of Avastin in patients with recurrent glioblastoma so that I could standardize the doses and the follow up schedule.

A few months later, I spoke with Dr. Henry Friedman [Duke University] at a conference and showed him the MRI scans of a patient who was on Avastin. He immediately grasped the significance of targeting angiogenesis, and, as they say, the rest is history.

I am so very grateful to Dr. Friedman and to my Air Force colleagues for acting on my observations so quickly and they were able to perform a much more rigorous clinical trial within a year, which led to the FDA approval of Avastin for glioblastomas four years later. But it is really all because of Les’s suggestion and Dorothy’s courage to step out into the unknown that I began to use Avastin in other patients. •
In our opinion...

There needs to be a wider, more flexible acceptance that brain tumours require novel approaches urgently and this is where advocacy is particularly relevant. Advocacy should not be a “dirty word”, component of the work of the international brain tumour community. Unless there is continual advocacy by patients, their families, caregivers and patient group representatives asking the awkward questions and pushing and prodding (politely but firmly) where they can, many of the other components of patient support will stagnate.

The place on the cancer map where brain tumours dwell is often cloaked in half light and shadows. It can be an isolated and arid region, desperately in need of the sunshine of hope. It can be an area where they can, many of the other components of patient support will stagnate.

In our opinion…

Additionally, many governments and major international and national cancer control organisations have prioritised prevention, screening and healthy living campaigns in the fight against cancer. These are all excellent initiatives of course. But not every cancer can be helped by this approach.

Brain tumours, for example, affect people randomly and there is no realistic screening for them. The cause of most primary brain tumours is unknown. And there is no known preventative option by healthy living, diet or exercise.

In the developing world, which is responsible for at least 70% of all primary malignant brain tumours, most patients have no opportunity whatsoever of accessing what would be regarded as the basic minimum standard of care for a brain tumour patient.

For brain tumours, the path should lead to focussed and determined advocacy which puts pressure on governments to increase their research funding. Advocacy can also engender productive collaborative efforts where possible.

Crucially, advocacy can lead to greater access to promising new therapies for brain tumour patients which, although they may not always save life, can extend survival with a good quality of life.

The IBTA proudly proclaims that it is essentially a patient advocacy and awareness-raising organisation. We trust that - in tandem with others - advocacy can engender productive collaborative efforts where possible.

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Dos and Don’ts for Communicating Bad News to Patients and Families

Walter F. Baile, MD, is Professor of Behavioral Science, and Director of the Interpersonal Communication And Relationship Enhancement (I*CARE) Program - Department of Faculty Development - The University of Texas M.D. Anderson Cancer Center, United States

Bad news is any news that seriously and adversely changes the patient’s view or expectations of the future.

Bad news refers not so much to the medical reality of the condition, but to its impact on the patient.

You can’t tell how bad bad news is or how badly it may affect the patient until you’ve already got some idea of what the patient’s perceptions and expectations of the situation are. The “S-P-I-K-E-S” protocol is an important tool that will make this interaction less traumatizing for the patient and family. When faced with delivering bad news to cancer patients, there are a number of useful points to pay attention to.

Things to Do

• S – “Setting” - Ensure privacy and provide comfort. Be prepared to listen and have tissues available. Be sure the patient is seated across the corner of your desk and closer to you than any family members. 
• P – “Perception” - Assess what the patient perceives about his situation. “Before I go into your test results, why don’t you tell me what you understand about the situation and what was said to you before the tests?” or “When you first started getting the headaches, what did you think was going on?” Use open-ended questions, “validate” by acknowledging and saying you understand the patient’s feeling and then give an “empathic” response. 
• I – “Invitation” - Before telling a patient bad news, find out whether they want to hear it. Permission allows the patient to decline the information. They may not feel up to it or may want to have family members present. It’s a signpost for setting the goal for the subsequent conversation. “Now, if it turns out to be something serious, would you like me to tell you what’s going on and how we plan to treat you?” or “I’d like to go ahead and tell you what we’ve found. Is that okay?”
• K – “Knowledge” - Use a “Narrative Approach” to explain the diagnosis, “Before I go into your test results, why don’t you tell me more?” to explore the present and allow the patient to connect the first and the second. An “Empathic Response” implies that you have detected and understood the patient’s feelings. It doesn’t mean that you feel the same way. It is an intellectual, sensitive response and it acknowledges those emotions without agreeing with them. Use the E-V-E sub-protocol. “Explore” with open-ended questions, “validate” by acknowledging and saying you understand the patient’s feeling and then give an “empathic” response.
• E – “Emotion” - An empathic response to the patient’s emotion such as, “That is obviously a shock,” is a compassionate way of aligning with the patient. Deal with any emotion when it occurs. First, identify the emotion that is present, second, identify the cause of that emotion, and third, respond in a way that shows that you have made the connection between the first and the second. An “Empathic Response” implies that you have detected and understood the patient’s feelings. It doesn’t mean that you feel the same way. It is an intellectual, sensitive response and it acknowledges those emotions without agreeing with them. Use the E-V-E sub-protocol. “Explore” with open-ended questions, “validate” by acknowledging and saying you understand the patient’s feeling and then give an “empathic” response.
• S – “Strategy and Summary” - Form an agreed “Strategy” to deal with the situation. Listen and acknowledge the patient’s feelings and check along the way to find out what effect it’s having on the patient. Summarize the discussion as this tells the patient you have listened and registered their concerns. Ask if there are any urgent questions. If the interview was upsetting and the patient is alone, ask if you can call someone to come get them. Make a clear contract for the next contact. Things to Avoid
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Things to Avoid

• Allowing interruptions (phone calls, pages, or answer a knock on the door)
• Interrupting the patient
• Making judgments like “You’re not supposed to be that angry about this,” or “You’re over-reacting”
• Giving bad news without asking if the patient wants to hear it first
• Ignoring the patient’s emotions
• Setting up unrealistic expectations; instead discuss the idea of supportive control
• Destroying hope. You can agree with the patient’s hope that his cancer won’t recur, without agreeing with his assertion that it won’t. Hope need not be equated with a cure for some patients.
• Allowing the patient to feel abandoned; instead reassure them of an ongoing therapeutic relationship
• Offering further treatment when it’s obvious that further treatment is futile
• Delivering bad news over the phone
• Remember that even though you are the bearer of bad news, you’re really not responsible for it. We may feel that we would like to distance ourselves from the patient’s situation, but we really should try to take care not to do so.
• Breaking bad news is a complex task. Because physicians do it many times over their careers, it’s valuable to have a strategy that produces a supportive atmosphere for the patient.
• The information above is a very condensed version of the strategies that you can find on The University of Texas M.D. Anderson Cancer Center’s Interpersonal Communication And Relationship Enhancement (I*CARE) website (www.mdanderson.org/icare) where you will find video demonstrations (using the “SPIKES” protocol and others) of various difficult conversations that clinicians encounter during their careers. The site offers free Continuing Medical Education credit.

Book - 100 Questions and Answers about Brain Tumors

“Book - 100 Questions and Answers about Brain Tumors” by Dr. Vance, MD, at the WFNO Conference, Edinburgh, when the IBTA was established. See a profile of Dr Stark-Vance in another section of the magazine and read about her connection with the identification of Avastin as being relevant for treating gliomas. How to obtain a copy: RRP $19.95 USD (pback). Available from Jones and Bartlett Publishers www.jbpub.com or try Amazon http://www.amazon.com (make sure you order the 2nd edition), 284 pages.

These wonderful photographs of American singer/songwriter and long term brain tumour survivor David Bailey were taken by another long term brain tumour survivor, Maxine Bailey, who lives in London.

When David came over to Great Britain in 2008 to do a concert tour for British brain tumour charities, the International Brain Tumour Alliance asked Maxine - who is unrelated to David - although they share the same surname - to shadow him for a day and snap the legendary performer as he explored some of London’s top sightseeing attractions.

A superb set of photographs – “Bailey on Bailey” – resulted and we are delighted to publish a few of them here for the first time.

Maxine was diagnosed with an oligodendroglioma in 2000, having suffered symptoms for two years previously. She underwent chemotherapy in 2004.

“The tumour diagnosis was obviously a huge shock,” said Maxine, “but having a brain tumour brought me into a different relationship with the world and gave me a different perspective on life. I came much closer to appreciating how beautiful the world is.”

“In fact, you could say the brain tumour saved my life because it gave me a new value on life and kicked me into a new dimension.

“It was after my diagnosis and that I turned to photography. Through photography I could show people a fresh, new world as I re-discovered it. I use photography as a meditative tool. I find it very therapeutic and it grounds me. I relate most of all to nature and environmental photography so it was a big challenge for me to concentrate on a human being when the IBTA asked me to do this series of photos of David Bailey. But David is such a great guy, is such a natural and has so much charisma that it was a real joy to capture him on film.”

Maxine Bailey and her partner Kerry Munn

On advice to newly diagnosed brain tumour patients, Maxine says: “You just need to believe that life isn’t over when you are diagnosed with this disease. Instead, life is just going to be different. Strange as it may sound, I have a new quality of life and am grateful for being able to cherish life now.

“I couldn’t do anything without the support of my long-term partner, Kerry Munn who is from New Zealand. When I was diagnosed with my brain tumour, I put in a request to the Universe for an angel and I got Kerry! He’s a fantastic guy and he is my angel!"
The CUHK Brain Tumour Centre was established in 2007 by the Department of Surgery at the Chinese University of Hong Kong. The Centre seeks to boost public awareness of brain tumours, provide support to brain tumour patients and raise funds for relevant medical research.

**Mission**
- To promote and conduct research activities related to tumours of the central nervous system (CNS).
- To provide training and overseas professionals in the management of patients with CNS tumours.
- To translate research advances into clinical benefits.

**Combined Neuro-Oncology Clinic**
A one-stop Combined Neuro-oncology Clinic was established in June 2009. This clinic provides a new, patient-oriented service that targets patients with malignant brain tumours who require multi-modality treatment (i.e., radiotherapy, chemotherapy or combined treatments). These patients are now seen by neurosurgeons, radiation oncologists and neuro-oncologists at one clinic, rather than having to pay multiple visits to different clinics for combined treatment.

**Clinical psychology service and counseling service**
We plan to provide psychology counseling service to our patients and family members starting the second half of this year (2010).

**Brain Tumour Awareness Program – Braintrekking**
This is the Hong Kong chapter of the global brain tumour awareness program, Walk Around the World for Brain Tumours, announced by the IBTA. We organized this annual walkathon since the first year in 2007, which was well received by the community with a growing number of participants and the amount of donations to our centre.

www.surgery.cuhk.edu.hk/btc
FOUND! The missing Matron’s Report Book in the landmark Rickman Godlee 1884 glioma operation case

Forgotten in an archive cupboard for many years, crucial evidence is re-discovered about a young brain tumour patient who made history.

In 2009, the IBTA wrote and published a booklet on “The First Documented, Modern-Day Brain Tumour Surgery for a Glioma”. This booklet was published to commemorate the 125th anniversary of surgeon Rickman John Godlee’s landmark operation on a young brain tumour patient in 1884 in London, UK.

The glioma operation carried out by Rickman John Godlee was the first documented surgical removal of a cerebral glioma based on localisation of neurological symptoms. The brain tumour surgery on 25th November 1884 marked a turning point in the treatment of glioma, and aroused enormous interest, not only among medical professionals but also the general public.

The IBTA booklet explains why the story, the Report could not be found. A slip inside (the book) reads: “This document is the only extant evidence of the operation performed on John Mitchell for Glioma on November 25th, 1884.”

We are delighted that this important piece of neuro-oncological history has now been found. It is hoped that the Matron’s Report Book will eventually go on display at the newly refurbished Rockefeller Library where it re-opens.

Kathy Oliver to say: “Just to let you know – today I found the Matron’s Report Book. It was a lucky and serendipitous break. I am now able to delve into the cupboards that hold the archives. Going in deep searching for any (old) examples of menus for staff and patients I picked up the diary (which isn’t marked on the outside) to see if it had anything to do with food – and it fell open at the page you are interested in. A slip inside [the book] reads: “This document is the only extant evidence of the operation performed on John Mitchell for Glioma on November 25th, 1884.”

A case of glioma patient John Mitchell was the first documented case of glioma surgery performed in the UK. It was performed on a 25-year-old farm labourer who had been identified by his general practitioner as suffering from a brain tumour.

The page from the Matron’s Report Book which describes the surgical nurse she hired to look after glioma patient John Mitchell in late November 1884.

A number of mysteries were solved when researching this booklet, notably the possible reasons behind the promulgation of the incorrect name of the brain tumour patient.

The 29th century Matron’s Report Book (left) with copies of the IBTA’s blue-covered booklet (published in 2009) on “The First Documented, Modern-Day Brain Tumour Surgery for a Glioma” which took place in 1884.

However, on 25th March 2010 Louise Shepherd (Manager, Library and Computing Services, University College London Institute of Neurology and Librarian at the Rockefeller Medical Library, the National Hospital for Neurology and Neurosurgery, Queen Square, London) emailed the IBTA.

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Christopher Reid - the British poet who lost his wife to a brain tumour

Earlier this year British poet Professor Christopher Reid won the prestigious UK Costa Book of the Year prize (worth £30,000 GBP - $47,000 USD) for his book of poems, “A Scattering”, about his wife’s illness with a brain tumour and the effect on him after she died in 2005. Christopher has given permission for the IBTA to quote from his poems in the magazine, which we have done below. His 62-page book is published by Arcte and the ISBN numbers are: ISBN-10: 0955455367 ISBN-13: 978-0955455360. The book is available via Amazon or other on-line book distribution agencies.

Christopher’s wife was the actress Lucinda Gane. In one of the poems he writes of the hospital where Lucinda willed her body to medical science:

My wife is in there, somewhere, doing practical work: her organs and tissues are educating young doctors or helping researchers outwit the disease that outwitted her. So it’s a hallowed patch of London for me now. In another he recalls her presence: You watched bad television, had me massage your neck and sewed lavishly beautiful patchwork quilts. When that quack put you on a punishing diet, you pedalled a borrowed exercise bicycle for however many static miles a day and learned Italian from a book supported on the handlebars. Your breakfast reading was a gardening encyclopedia which took up half the table; you absorbed the Linnaean taxonomy along with your grapefruit and coffee. Two or three things at the same time. Can’t you now somehow continue to be both dead and alive?

PROFESSOR JEAN-YVES DELATTRE
Professor of Neurology, Attending Neurologist, and Chairman of the Fédération of Neurology “Mazarin”, Salpêtrière Hospital, Paris, France

IBTA: Where did you spend your childhood?
J-YD: I spent my childhood in various provinces of France, following my parents with my four brothers. I enjoyed living in small cities of the so called “France profonde” where I would like to go back to later.

IBTA: Did you come from a family environment that had a connection with medicine or research?
J-YD: No. Going to medicine was seen by my relatives as a curious idea as compared to business or engineer training which was thought to be more prestigious, but they supported me.

IBTA: What attracted you to medicine and, later, to the brain tumour area?
J-YD: A very primitive and instinctive need to care. Nothing to do with philosophy, religion or any kind of moral. When I meet a caregiver, whatever his or her status, I can identify almost immediately as if we are the same. I am very sensitive to these emotional challenges with our family. Patients and their families are very helpful. The link is often strong. Patients and their families know well our weaknesses and failures, although patients and families know we do our best. I preciously keep the sequelae. We are rather well organized and collaborate together in the world neuro-oncology community. The information circulates and we now have substantial public support. The wealth of basic knowledge acquired over the last ten years is really considerable. I have no doubt that this knowledge will bring therapeutic advances. If we accept transient disappointments and improve our ability to rapidly bring new agents to the patients (“therapeutic highway”), particularly with targeted agents, we should be able to make an additional step towards “the cure without sequelae” goal.

IBTA: How do you cope with the emotional and psychological challenges to you personally arising from your work?
J-YD: It is really very difficult. Working as a team is necessary to share these emotional challenges with professionals. It is not possible to share these feelings with our family. Patients and their families are very helpful. The link is often strong. What amazes me is to realize that although patients and families know well our weaknesses and failures, they still stand close to us, almost unconditionally if they consider that we do our best.

IBTA: Do you anticipate any significant breakthroughs in brain tumour therapies in the next ten years? If so, in what area?
J-YD: I am optimistic. The era of pioneers is behind us. We are rather well organized and collaborate together in the world neuro-oncology community. The information circulates and we now have substantial public support. The wealth of basic knowledge acquired over the last ten years is really considerable. I have no doubt that this knowledge will bring therapeutic advances. If we accept transient disappointments and improve our ability to rapidly bring new agents to the patients (“therapeutic highway”), particularly with targeted agents, we should be able to make an additional step towards “the cure without sequelae” goal.

IBTA: What amazes me is to realize that although patients and families know well our weaknesses and failures, they still stand close to us, almost unconditionally if they consider that we do our best.

IBTA: How do you relax? Do you play music, go for walks, sail a boat? Do you have a hobby?
J-YD: Family first. I am also fascinated by nature. Gardening is my hobby. Spring! Life always wins! In each country where I go, I bring back a plant and try to adapt it to the Parisian climate. It does not always work.

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Finding a Cure for BRAIN TUMOURS
Funding research and sharing information. Inspiration and hope for those affected by high-grade brain tumours

Astrofund was founded in 2001 by Kathy Bouron and since then has funded 28 research projects in the UK. We also have an online support group for those whose loved one was touched by astrocytoma or glioblastoma multiforme. The group includes over 250 patients, carers, families and professionals from around the globe.

http://www.astrofund.org.uk/astrofund/support

Low-grade astrocytomas can be unrecognised for many years before symptoms suddenly emerge and can leave the patient and family unprepared. They can cause progressive mental and physical problems and sometimes are a sign of an underlying more malignant form of brain tumour.

Astrofund is working hard to raise funds to help end the anguish of those living with brain tumours.

For more details contact Christine Foreman on (01449) 372767.
Email: info@astrofund.org.uk www.astrofund.org.uk

BT Buddies

BT Buddies, based in the United Kingdom, was started by Natalya Jagger following the passing of her best friend Andrew’s daughter Rose from a glioblastoma multiforme.

BT Buddies provides online information on high grade brain tumours for patients, families and caregivers.
“An interest in everything brain…”

Professor Michael Brada
Royal Marsden Hospital, London, United Kingdom

IBTA: Where did you spend your childhood?
MB: I grew up behind the Iron Curtain in unformed Czechoslovakia.

IBTA: Did you come from a family environment that had a connection with medicine or research?
MB: Both my parents were doctors, working in socialised medicine where the principle was equal access to medical care for everyone with no fee at the point of delivery. In a communist society there was a strong principle of equality and the value of manual work, and the intelligentsia was paid less than the proletariat! My father would have been an academic had it not been for the disruption of the Second World War.

IBTA: What attracted you to medicine and, later, to the brain tumour area?
MB: Since my teenage years medicine was the only career for me. As for brain tumours - I guess serendipitously, I always had an interest in everything brain, and this combined with inspiring teachers and opportunity at the right time.

IBTA: How do you relax? Do you play music, go for walks, sail a boat? Do you have a hobby?
MB: I am a cyclist - a bike ride home after a busy day blows the cobwebs away. And yes, I love winter and summer mountain sports; and yes, I play chamber music with friends.

IBTA: How do you cope with the emotional and psychological challenges you personally arising from your work?
MB: Who knows - my family probably takes the brunt....

IBTA: Do you anticipate any significant breakthroughs in brain tumour therapies in the next ten years? If so, in what area?
MB: We are in a rapidly changing research landscape with personalised medicine underpinned by the human cancer genome project finding its way gradually into all oncological fields. Whether this will translate into advances in brain tumour therapy will depend on funding; breakthroughs may become part of it but are unpredictable. While the potential for significant progress is great, I fear that the growth in private medicine has a negative influence on progress by promoting treatment approaches of commercial interest and curtailing academic freedom and objectivity.

A step closer... out of the shadows on the Camino de Santiago

The Souls and Shadows Foundation in the United Kingdom supports charities which enhance the lives of the terminally ill through the use of music therapy. The Foundation was set up in memory of Paul Barlow-Olsen who died of a gliobastoma multiforme brain tumour on 23rd December 2006. Paul Barlow, the Souls and Shadows Foundation Secretary Treasurer, and four friends recently walked a portion of the Camino de Santiago. They started at St Jean Pied de Port in France and crossed the Pyrenees through Pamplona to Los Arcos. Paul said: “This year we continued from Los Arcos reaching Villabilla de Burgos and walking 137 kms in a week. As you probably know the Camino (all 778 kms) has been a Pilgrimage Way since the Middle Ages the objective being the tomb of St James the Apostle in Santiago de Compostela. It is a really well way-marked and you hardly ever need a map...it is still more than a walk because of the many interesting characters you meet along the way.” Last year we met a young woman who had already walked 1,000 kms starting in Switzerland and still had 700 to go - another woman from Italy was doing it because she had miraculously been saved after being given a terminal prognosis by her doctors. It really is quite inspiring. Next year we are thinking of getting sponsored to raise money for “Souls and Shadows” when the target is to walk 174.5 kms to Leon. Souls and Shadows donated their 785 kms to the Walk Around the World for Brain Tumours in memory of Caspar Barlow-Olsen.

In 2007 - the year of the first Walk Around the World for Brain Tumours – another brain tumour supporter walked a portion of the Camino de Santiago. Jeralyn O’Connor donated 1,400 kms to the World Walk and in the process raised funds in support of the UK-based Brain Tumour Research Campaign. Paul added: “This year we have also all walked from Frimley Green in Surrey to Chantont on Otmoor in Oxfordshire (UK) on our ‘Home to Home’ travels. That was 68.25 miles or 109.25 kms which for the five of us is 546.25 kms.”

www.stopbriantumors.org
www.stop-hersentumoren.nl

Peng-Yu
Taiwan

IBTA: What kind of brain tumour do you have and when was it diagnosed?
P-Y: I was diagnosed with an Astrocytoma near the sella at 1993. At that time, I was 11 years old.

IBTA: How has it affected your life?
P-Y: Besides poor memory and physical decline, I got Epilepsy which obstructs me getting a driver’s license and finding a job.

IBTA: Do you receive adequate support?
P-Y: Yes, I got adequate support from my family, medical team group, and friends.

IBTA: Have you established contacts with people with a similar diagnosis?
P-Y: Yes, I met friends with a similar diagnosis at the (Taiwan) Childhood Brain Tumour Association.

IBTA: Have you any tips or suggestions for newly diagnosed brain tumour patients?
P-Y: Since you get the brain tumour, you have to accept it. You are not the same as before.

IBTA: What are the first three things on your wish list in relation to this disease?
P-Y: The first thing on my wish list is to have my personal vehicle. The second is finding a suitable job and being able to stand alone. The third, while I am no longer continue working, I wish I can still be able to maintain my life.

IBTA: How do you relax? Do you play music, go for walks, sail a boat? Do you have a hobby?
P-Y: I like listening to music, watching TV, reading jokes, and surfing the internet.

Be Informed

Read the monthly E-News bulletin (available in six languages or in print by writing to IBTA) for information from within the international brain tumour community and not found elsewhere.

Go to the IBTA website (www.theibta.org) and click on the subscriptions link.
Help us reach our target of a quarter of a million kilometres with a Walk Around the World for Brain Tumours!

Organise a sponsored walk to raise awareness of the challenges of this disease.

Walks can be done anytime between 1 January & 6 November 2010!

The IBTA doesn’t want any of the funds raised. These should go to local brain tumour support groups or relevant research institutions. Walks can also take place during the International Brain Tumour Awareness Week (31 October to 6 November) 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 or Co-Director as below. The IBTA requires no financial commitment or fee to be paid to us by you. All we are asking for is your enthusiasm in supporting and promoting these events and for allowing us to add your name to our list of supporters.

For more information please visit www.theibta.org or contact chair@theibta.org or kathy@theibta.org
Accurate Brain Cancer Cure
Accurate Brain Cancer Cure has a singular focus - to hasten the discovery of a cure for brain cancer.
www.abcc3.org

Adult Brain Cancer Support Association
The ABC Support Association is located in South Australia and is focused on giving support, encouragement, help and guidance to adults diagnosed with brain cancer, their families, friends and carers.

Adult Ependymoma
A website dealing primarily with adult ependymomas.
www.sites.google.com/site/adultependymoma

Ali's Dream
A not-for-profit organization established to raise funds for research into childhood brain tumours.
www.alisdream.f2s.com

Allinee
Allinee (Association Lilloise de Neuro-Oncologie) is a patient-oriented organisation providing information and support to brain tumour patients and their families in the Lille area (north of France).
www.allineeasso.fr

American Brain Tumor Association
Founded in 1973 out of a desperate need, the American Brain Tumor Association exists to eliminate brain tumors through research and to meet the needs of brain tumor patients and their families.
www.abta.org/index.cfm

Andrea’s Gift
A brain tumour charity active in the Yorkshire area of the UK.
www.andrewcostfuk.org.uk/index.html

Andrew McCartney Trust Fund
Funds scientific and medical research into the causes of brain tumours, and builds public awareness of the challenges of this disease.
www.andrewmccartneyphotos.co.uk

Archives
Here at the IBTA, we’ve gathered a list of brain tumour organisations offering support and advice, so you don’t have to!

Angels Among Us
The Angels Among Us UK and Family Fun Walk is a celebration of life, strength, courage and commitment. This volunteer organisation was established to support the mission of hope at the Preston Robert Tisch Brain Tumor Center at Duke Durham NC, USA.
www.angelsamongus.org

ARTC Sud
Ce site vise à adresser à tous ceux qui souhaitent s’informer sur les tumeurs cérébrales cancéreuses et sur la recherche en neuro-oncologie et à ceux qui dévouent faire progresser cette recherche.
www.artcsud.asso.fr/index.htm

Astro Fund
A UK group offering information, inspiration and hope to all those living with a low-grade brain tumour.
www.astrofund.org.uk

Barbara DiStase Memorial Walk
This walk is in memory of Barbara DiStase and will be held on August 2, 2009 in New Jersey (USA).
www.barbaradistase.com

Brain and Spine Foundation
The (UK) Brain and Spine Foundation seeks to develop research, education and information programmes aimed at improving the prevention, treatment and care of people affected by disorders of the brain and spine and to stimulate the greater allocation of resources across all neurological disorders.
www.brainandspine.org.uk

Brain Tumor Action Network
The Brain Tumor Action Network is a US-based not-for-profit organization established to bring awareness to the general public about brain tumors and to educate and empower brain tumor survivors, their families and friends.
www.braintumor.org

Brain Tumor Awareness Organization
The Brain Tumor Awareness Organization is an on-line resource for raising brain tumor awareness and gaining support.
www.braintumorawareness.org

Brain Tumor Foundation for Children
The Brain Tumor Foundation for Children Inc is a Georgia (US) based support, information, and fund-raising organisation for children with brain tumors.
www.brain肿瘤kids.org

Brain Tumor Resource and Information Network
Based in Virginia, USA.
www.brainlife.org/index.html

Brain Tumor Society
The Brain Tumor Society exists to find a cure for brain tumors. It improves the quality of life of brain tumor patients, survivors and their families and raises funds to advance carefully selected research projects.
www.brain tumors.org/GenetqMenu

Brain Tumor Action
A voluntary group based in Scotland which concentrates on support, counselling, education, information and research.
www.brain tumora ction.org.uk

Brain Tumour Alliance Australia
Brain Tumour Alliance Australia (BTA) is the only national brain tumour patient and caregiver organisation in Australia.
www.btaa.org.au

Brain Tumour Association (Western Australia)
The Brain Tumour Association (Western Australia) is a support group for patients and caregivers.
www.brain tumourwa.com

Brain Tumour Foundation of Canada
The Brain Tumor Foundation of Canada is the major non-government brain tumour organisation in Canada.
www.brain tumourfoundation.ca

Brain Tumour Foundation of India
A support group for patients and Doctors.
www.braintumourindia.com/introduction.htm

Brain Tumour Research
Brain Tumour Research specifically funds brain tumour research at UK centres to accelerate progress and improve patient treatments and outcomes.
www.brain tumourresearch.org

Brain Tumour UK
Formally UKBTS. A UK-based organisation involved in research, education and support.
www.braintumour.org.uk

Brainlife
An electronic newsletter which lists relevant articles from professional publications and is archived at the above website.
www.braintumourfoundation.org

Braintrust
The Meg Jones (UK) tumour charity - supports people diagnosed with critically ill brain tumours to be able to receive surgical care.
www.braintrust.org.uk

British Acoustic Neuroma Association
BANA is organised and administered by people affected by acoustic neuroma, is a registered charity and exists for mutual support, information exchange and listening.
www.bana-uk.com

BT Buddies
A site dedicated to discussing survivorship, treatment options available now and those options on the horizon that she hopes.
www.btsurvivor.com

Canadian Alliance of Brain Tumour Organisations
The Canadian Alliance of Brain Tumour Organisations (CABTO) is an alliance of volunteer organizations, dedicated to enhancing the quality of life of brain tumor patients and families.
www.cabto.ca

Charles Warren Brain Tumor Awareness Foundation
The Charles Warren Brain Tumor Awareness Foundation is a non-profit organization based in Georgia, USA. It seeks to “significantly raise awareness of the disease of brain tumors so that cure can be found more quickly.” It currently supports the Preston Robert Tisch Brain Tumor Center at Duke University.
www.charleswarrenfoundation.org

Child’s Challenge
Charlie’s Challenge is a UK based charity which raises money to finance urgently needed research into children’s brain tumours.
www.charlieschallenge.org

Childhood Brain Tumor Foundation
The Childhood Brain Tumor Foundation of Maryland “supports and funds basic science or clinical research for childhood brain tumors.”
www.childrenbrainfoundation.org

Children’s Brain Tumor Foundation
The NY-based CBTF, founded in 1988, seeks to “improve the treatment, quality of life and the long term outlook for children with brain and spinal cord tumors...”. www.cbtf.org

Clinical Trials and Noteworthy Treatments
Treatment for Brain Tumors
Regarded as one of the most comprehensive brain tumor websites in the English-speaking language.
www.virtualtrials.com

Desmoplastic Infantile Ganglioglioma
Website for Gareth Brandon (Fife, Scotland) who has a rare Desmoplastic Infantile Ganglioglioma paediatric brain tumour.

Deutsche Hirntumorhilfe e.V.
A non-profit, German-based independent organisation, which raises funds for the advancement of neuro-oncological research and the improvement of medical health care for brain tumor patients.
www.hirntumorhilfe.de

Emory Brain Tumor Support Group
The Emory Brain Tumor Support Group (Georgia, USA) provides an opportunity for information, sharing and support among patients diagnosed with a brain tumor, their families and caregivers.

Ependymoma on-line support group
As on-line support group facilitated by Bruce Blount.
www.sites.google.com/site/adultependymoma/p

Fitzy’s 5 km Run/Walk
This annual run/walk raises funds for brain tumor research and support activities in honour of 20 YO Lauren M Fitzgerald who passed away in 2005. Funds are administered through the Berkis County Foundation. www.fitza5kmrunwalk.org

Glioblastoma Foundation Michele Esnault
A non-profit, German-based independent organisation, which raises funds for the advancement of neuro-oncological research and the improvement of medical health care for brain tumor patients.
www.glioblastoma-germany.de

Gray Matters Foundation
The Gray Matters Foundation is a 501(c)3 organization whose mission is to support and empower people impacted by brain tumors through outreach, awareness and assistance program.
www.graymattersfoundation.com

Hammer Out
Hammer Out is a UK brain tumour charity active nationally and in the South West region of England.
www.hammerout.co.uk

Have A Chance
Have A Chance is a New Jersey (US) based not-for-profit organization dedicated to helping individuals and families impacted by a brain tumor find the most appropriate and innovative therapies.
www.haveachance.org

Head Start
Intended to give sufferers in New Zealand a Head Start when they are battling brain tumours.

Herentsumor.nl
A patient-oriented organisation in the Netherlands whose aim is to prevent and cure brain tumours.
www.herentsumor.nl

The Alicia Pueyo Fund (Fondo Alicia Pueyo)
This Spanish organisation was created with the mission to promote and support research on childhood brainstem tumors, in order to develop new treatments and drugs that may offer an early cure for all children affected by this terrible disease.
www.fondodialiciapueyo.org/e_inicio.php

GFME
Globastoma foundation Michela Einau is a French-speaking group for brain tumour patients.
www.gfme.free.fr

Glio Blast Off
The US-based Glio-Blastoff Sit Run/Walk has been created to raise money for brain cancer research.
www.braincancer5k.com/index.html

Glioma Support Group
The international forum dedicated to those affected by low-grade gliomas.
www.health.groups.yahoo.com/group

Gray Matters Foundation
The Gray Matters Foundation is a 501(c)3 organization whose mission is to support and empower people impacted by brain tumors through outreach, awareness and assistance program.
www.graymattersfoundation.com

Hoeve Chamberwalk
Intended to give sufferers in New Zealand a Head Start when they are battling brain tumours.

Hersentumor.nl (The Netherlands)
A patient-oriented organisation in the Netherlands whose aim is to prevent and cure brain tumours.
www.herentsumor.nl
**Making Headway**
Making Headway Foundation Inc. is a non-profit (501(c)3) US-based organization dedicated to helping kids affected by brain tumors.

**Paediatric Brain Tumour Foundation of the US**
Seeks to find the cause and cure of brain tumors in children.

**Paediatric Low Grade Astrocytoma Foundation**
The US based Paediatric Low Grade Astrocytoma Association (PLGA) seeks to raise awareness, funding, and find a cure for this disease.

**Meagan’s Walk**
Creating a Circle of Hope - Meagan’s Walk, held on Mother’s Day, raises awareness about paediatric brain tumours and funds for research. Participants conclude the walk with a circle around Sick Kids Hospital, Toronto, Canada.

**Meningioma Mommas**
Meningioma Mommas is a 24/7 online support group for all those affected by meningioma brain tumors. The non-profit organization is also committed to raising funds for meningioma specific research.

**Meningioma UK**
The only UK organisation for support and information for patients with meningioma tumours of the brain and spine, Thirty per cent of all primary brain tumours are meningiomas.

**Michael Quinlan Brain Tumour Foundation**
The Michael Quinlan Brain Tumour Foundation is dedicated to empowering those persons who have been affected by brain tumour.

**Monmouth and Ocean County Brain Tumor Support Group**
The Monmouth and Ocean County Brain Tumor Support Group is a US based (New Jersey) brain tumor support group.

**National Brain Tumor Society**
US based patient organisation with information about treatment, medical centres, clinical trials and survivor network.

**Nikki’s Hope**
The ultimate goal for Nikki’s Hope Foundation is to raise funds for research to find the cause and cure for brain tumours and to assist families of children battling brain tumours.

**Ohio Brain Tumor Foundation**
OKBTN is dedicated to meeting the needs of Ohioan families, caregivers and patients affected by primary or central nervous system tumors.

**STOPhersentumoren.nl**
Provides support services for people affected by brain tumour.

**The Kelly Heinz-Grundner Brain Tumor Foundation**
The Kelly Heinz-Grundner Brain Tumor Foundation seeks to raise public awareness, support individuals and families of individuals facing this disease, and to support advanced research into brain tumors.

**The Kevin J Mullen Memorial Fund for Brain Tumor Research**
The Kevin J. Mullen Memorial Fund for Brain Tumor Research, based in the USA (Lancaster, Ohio), conducts an annual 5 km run/walk from which the proceeds go to brain tumor research.

**The Tanner Seebaum Foundation**
The Tanner Seebaum Foundation is a US based (Centennial, Colorado) non-profit organisation that strives to fund medical research that will lead to a cure for this terrible disease and place special emphasis on the treatment of Epiphymoma and Glial tumours of the brain and spine.

**The Zimbabwe Brain Tumor Association**
The Zimbabwe Brain Tumor Association, whose motto is “achieving through hope and strength”, may be contacted through Christine Mungoshi: omungoshi@zaa.net (substitute @ for at).
The International Brain Tumour Alliance (IBTA) was established during the conference of the World Federation of Neuro ONcology held at Edinburgh (UK) in May 2005. It seeks to be an alliance of the support, advocacy and information groups for brain tumour patients and carers in different countries and also includes researchers, scientists, clinicians and allied health professionals who work in the area of brain tumours.

Statement of principles:

1. We seek to achieve for brain tumour* patients, their families and their carers a wider public recognition of the specific challenges which they face in dealing with their disease.

2. We support moves towards greater international collaboration between brain tumour support, advocacy and information groups.

3. We pledge to work to advance these aims in co-operation with like-minded organisations and individuals, including relevant government agencies, health professional organisations, pharmaceutical companies, cancer organisations, clinicians and research institutes and other patient advocacy organisations.

4. We aim to offer encouragement and hope to those in the international brain tumour community who reside in countries where brain tumour support, advocacy and information groups do not yet exist, helping ensure that no-one who is living with a brain tumour feels isolated and forgotten. We also aim to encourage the creation of brain tumour/CNS support groups in countries where they do not exist.

5. We seek a greater emphasis by research bodies in identifying causes of brain tumours and the development of more effective therapies, and also seek to encourage greater collaboration among researchers to reduce duplication. We seek a greater input of funding from the community, governments and industry, to support such research and development.

6. We advocate the development of improved access to a multi-disciplinary specialist range of services, including palliative care, rehabilitation (speech, neuropsychology, occupational therapy, physiotherapy, etc) and psychosocial support, to ensure that services are at all times appropriate to the needs of people living with a brain tumour and their families.

7. We support the development and implementation of a system of standardized data collection on benign, low-grade and malignant CNS tumours, to serve as a foundation for research that promotes improved care and treatment and the development of more effective therapies, and also seek to encourage greater collaboration among researchers to reduce duplication.

8. We support the development of a database of research projects relevant to brain tumours and encourage all those undertaking such research to be members of their relevant professional organisation.

9. We intend that each group in the collaboration project will continue to serve the brain tumour community in accordance with their own purpose. But at the same time, we acknowledge that there is strength in numbers and that each participating group can contribute to the power of the single collaboration effort for the good of brain tumour patients, their families and carers.

10. We seek to instill a greater measure of hope within the international brain tumour community by celebrating the courage and achievements of brain tumour survivors, sharing knowledge and working together to achieve progress.

11. We pledge our support to those charged with the responsibility for developing an appropriate international collaborative structure so that these objectives may be achieved. We see the organisation as being collaborative, rather than hierarchical.

* Any reference to the words ‘brain tumour’ includes all Central Nervous System (CNS) tumours.
THE BRAIN TUMOUR PATIENTS’ CHARTER OF RIGHTS

Introduction: There are a number of documents dealing with patients’ rights, some of which touch on the rights listed here. But this Charter has been drafted from the point of view of the brain tumour patient with particular consideration for the difficulties which sometimes arise in the brain tumour journey. The IBTA has sought to ensure that the Charter will have worldwide relevance but we are mindful that many countries lack basic health facilities and the specialists and facilities relevant to the treatment of brain tumours. The Charter therefore represents an aspirational ideal towards which we should work towards. While asserting our rights we acknowledge that no rights can exist in human society without responsibilities.

(1) My diagnosis and prognosis should be conveyed to me with accuracy and in a compassionate manner, and preferably by an experienced clinician or specialist. I have the right to ask questions and receive appropriate answers at any point. I have the right to an interpreter if one is available.

(2) I have the right to maintain hope and to be supported in that hope by my medical team.

(3) I have the right to receive a correct diagnosis and treatment in a timely manner. I have the right to be included in the decision making process for my care.

(4) I have the right to access the accepted standard of care in my country, no matter my age or ethnicity.

(5) My option to access care will be based on need, and not my ability to pay for it.

(6) I have the right to be told by my doctor about all available relevant treatments if he/she is aware of them in my country of residence, whether they are reimbursed by my country’s national health system or by my private medical insurance, or not.

(7) I have the right to receive treatment and medication to relieve nausea, seizures, and brain swelling in particular, and other symptoms.

(8) I have the right to be accompanied to my appointments by a family member or caregiver of my choice who may help me recall all that is discussed. I have the right to take notes and/or record the proceedings.

(9) Either my or my legal guardian’s informed consent is required prior to any treatment procedure, I will be informed if clinically-relevant delays in my treatment are expected and will be informed of alternative service providers who may be able to provide services at an earlier time.

(10) I have the right to multidisciplinary care, which may include - apart from my medical team’s help - support from other specialists and information about relevant support groups.

(11) I have the right to be provided with the name and contact details of a staff member at my treating facility who may be able to answer urgent questions at times other than scheduled consultations.

(12) I have the right to be given copies of all my medical records, including radiology reports, pathology reports, both histopathology and genetic analysis, and digital copies of all my scans if that process is available. If I have donated tissue or any other bio-specimen for research or clinical trial purposes I have the right to receive available, easy to understand information about the genetic characteristics of my tumour should I wish to have that information.

(13) I have the right to express my opinion on the level of care that I receive at an institution without fear of retribution, and will be given information on the means of expressing this opinion to management level staff.

(14) I have the right to ask that my brain tumour is properly registered in my country’s cancer registration records, whether it is benign or malignant.

(15) I have the right to be told about relevant clinical trials available in my current treatment facility and offered a place if I meet the inclusion criteria, or be directed to the contact details for a trial taking place elsewhere to which I might be suited.

(16) I have the right to further opinions, including the right to be informed by a specialist if he/she believes they do not have the skills necessary to perform an operation, or administer a therapy, and to be given the name of another specialist or treatment facility from whom and from where such skills will be available.

(17) I have the right not to be discriminated against in my community or my workplace because I have a brain tumour. However, I acknowledge that my brain tumour might render me unable to perform employment or tasks of which I was previously capable.
Brain Tumours
You can do something to raise awareness.

International Brain Tumour Awareness Week
31 October – 6 November, 2010