Brain Tumour
2005 - 2010 Anniversary Issue
World Edition 2010

Inside this Issue

Brain tumour specialists from around the globe share their thoughts

David M Bailey
a patient’s plea

Breaking bad news
dos and don’ts for doctors

Brain tumour organisations around the world and the people who lead them

PLUS: News of the international brain tumour community and more...

You are not alone on this journey...

Brain tumour patients
SPEAK OUT

Produced by the International Brain Tumour Alliance:
“Greater Knowledge, Greater Collaboration, Greater Hope.”
Walk Around The World
For Brain Tumours

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 and funds for more research and support.

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

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...and many more articles of interest to the international brain tumour community

Photos from previous Walks Around the World

Magazine designed by Megan Hedges meggi_ann@hotmail.com
Dear Reader,

Welcome to this magazine that is intended for the international brain tumour community. It has been produced by the International Brain Tumour Alliance (IBTA), which seeks to bring together all components of the community so that a more rapid advance can be made towards finding a cure for this devastating disease.

The magazine has been written from the point of view of the patient, the family and caregiver, and so there are many articles that will illustrate how other people – perhaps on the other side of the world – are coping with similar challenges.

There is other material in these pages that will be of interest to clinicians, neurosurgeons, and all those who treat brain tumours, such as little known facts about people who are at the forefront of developing new treatments and who feature prominently in the scientific literature. This magazine is an experiment, to see whether or not we have arrived at a balance of content that has a broad appeal. Please give us your feedback.

If this initial production is received positively then we will give serious consideration to making it a regular publication.

While some of the more difficult aspects of this disease are discussed within these pages, we do believe that you will be inspired by the numerous stories of hope and optimism which are also featured here.

Through the generosity of our funding organisations we have been able to distribute the publication widely among those who may be interested in its subject matter. We wish to thank those companies most interested in its subject matter. We wish to thank those companies most interested in our work. We hope that they will provide insight, inspiration and information to our readers.

It has been produced by the International Brain Tumour Alliance (IBTA), which seeks to bring together all components of the community so that a more rapid advance can be made towards finding a cure for this devastating disease.

For further details of the IBTA’s sponsorship policy please see www.theibta.org

For extra single and bulk copies of this magazine and enquiries about postage and freight costs please contact chair@theibta.org or kathy@theibta.org

PS: The articles in this magazine are not inserted in any particular order of importance. We think they all make excellent reading and if you should talk through this publication from the back, rather than the front, you will find articles which are every bit as important as those at the beginning. All are excellent in their own way and we hope they provide insight, inspiration and information to our readers. Items in the magazine (except those with original copyright) may be reproduced for the benefit of patients and caregivers as long as appropriate credit is given to the IBTA. Posters included in the magazine may be reproduced.

The International Brain Tumour Alliance (IBTA) is grateful for grants from the following companies:
How the IBTA was established and what it does

The IBTA had its origins when two people met up in London in 2004, brought together by their common belief that it would be useful to try and link the various national brain tumour groups and to improve advocacy and information for the needs of brain tumour patients, their families and caregivers around the world.

Denis Strangman’s wife Margaret was diagnosed with a glioblastoma multiforme brain tumour in 2000 in Australia and died in 2001. Later, Denis started importing brain tumour patient handbooks and literature from the USA and freely distributing them in Australia. With several other people he established a national patient and caregiver group and became its inaugural Chair.

Meanwhile, in the UK, Kathy Oliver’s then 24-year old son Colin was diagnosed with an astrocytoma brain tumour in January 2004 and, like many before and since, Kathy went in search of information on the Internet discussion groups where she came across Denis.

The IBTA takes shape

In 2004 Denis travelled to Dublin for a meeting of the then Cancer Against Cancer (UICC) and later to the Wimbledon brain tumour conference held in Edinburgh, Scotland. With the support of neurologist and local conference organiser Dr Robin Grant the yet-to-be-formed IBTA had a display at the conference and promoted the inaugural meeting of the IBTA to be held during a lunch break.

Denis Strangman again visited from Australia, this time with Tim Downing whose young daughter had passed away from a brain tumour. Denis first made a long detour route to Edinburgh via the USA discussing the proposed new group idea.

The IBTA is established

At the same time he met Elisabeth Ritz and Carrie Sessine of Ritz Communications who advised Schering Plough in community relations areas. At the Edinburgh WFNO conference Denis, Tim and Kathy were assisted by Alan Gow, a local organiser with the Macmillan cancer support group and by Robin Grant from the Neuro Oncology Translational Research Unit of the University of Edinburgh.

Neither the Schering Plough nor the other neuro oncology organisations were interested in the IBTA and refused to support it.

Elisabeth Ritz, Carrie Sessine, Tim Downing, Dr Robin Grant, Robin Grant, with Rob Tufel in San Francisco, the then CEO of the National Brain Tumour Foundation and now with the Ben and Catherine Ivy Foundation.

He also discussed the idea of the new group with Naomi Berkowitz, at the time the CEO of the American Brain Tumour Association in Chicago (now succeeded by Elizabeth Wilson – see later in the magazine).

Denis also visited Joy Schmidt (succeeded by Cathy Cantone) at the Schering Plough (now MSD Oncology) headquarters in New Jersey and received sufficient indication of potential support should the proposed group be established.

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In Australia who smoothed the way for Denis’s visit to the New Jersey company headquarters. Tragically and ironically, Hubert later died from a glioblastoma brain tumour and the Company has created an annual memorial award in his honour for an oncology trainer to travel overseas and obtain experience.

Hubert Stuerzi who encouraged his graphic design students to enter the competition. Tony had recently experienced the loss of a family member to a brain tumour.

The entry from one of his students, Rachel Aubrey, was selected as the winner. Rachel said that the logo she designed “symbolizes togetherness. It shows an alliance of people, arms around each other, bound by the same cause”.

Before the IBTA could do very much to establish itself on the world stage it became fully involved with the main UK brain tumour groups in campaigning for approval by the National Institute of Health and Clinical Excellence (NICE) of the new concomitant therapy of radiation and temozolomide which had been proven in the groundbreaking EORTC-NCIC clinical trial led by Drs Roger Stupp, Warren Mason and others. Those specialists, together with others such as Dr Michael Weller, Dr Michael Barton and Dr Peter De Deyn provided information about the use of the concomitant therapy in their respective countries which illustrated the minority position into which the UK was in danger of falling.

Ongoing projects and activities

After approval for the concomitant therapy was achieved in 2006 in the UK (although it was initially rejected by NICE), to entice the industry the IBTA in 2007 inaugurated the first Walk Around the World for Brain Tumours and the first International Brain Tumour Awareness Week. Both projects were supported by almost 100 patient and professional organisations from 23 countries.

The World Walk more than achieved its symbolic mileage target with 22,600 people walking a combined distance of 114,167 kms – two and a half times the distance around the world at the Equator. This innovative project helped promote global awareness of the challenges of brain tumours and at the same time, raised much-needed funds for more research into this disease and more support for patients, their families and caregivers.

These two events - the Walk and the Week - have now become a regular annual fixture in the brain tumour community and by the end of 2010, the IBTA’s number of supporting organisations around the world had grown to 182. None of the funds accumulated from the sponsored walks comes to the IBTA.

Another project which the IBTA initiated in the early years was to commission research by the Central Brain Tumour Registry of the United States

The IBTA logo designer Rachel Aubrey designed the logo which shows an alliance of people, arms around each other, bound by the same cause”. The logo re-designed “symbolizes togetherness. It shows an alliance of people, arms around each other, bound by the same cause”.

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To promote its annual projects and to convey a patient and caregiver perspective, where possible, the IBTA attends and exhibits at the key scientific conferences relevant to the brain tumour community, including the American Society of Clinical Oncology (ASCO), European Association of Neuro Oncology (EANO), European CanCer Organisation (ECOC)/European Society for Medical Oncology (ESMO) Action Against Rare Cancers and the European Cancer Patient Coalition’s (ECPC) Action Group on Rare Cancers. Officers of the IBTA also sit on various advisory committees including the National Board of Cancer Voices Australia (a cancer patients’ advocacy group); the European CanCer Organisation’s Patient Advisory Committee (ECOC PAC); the British Neuro Oncology Guidelines Development Group (which is formulating national, peer-reviewed guidelines for four rare brain tumours); an Australian government advisory committee dealing with palliative care medications; the Strategy Group of Cancer S2 (a UK-based umbrella group of charities and not-for-profits focusing on rare cancers); Rare Disease UK’s Working Group on Patient Care and Information, and the committee for developing Australian clinical practice guidelines for glioma which were released recently under the Chairmanship of Professor Michael Barton.

The IBTA seeks to encourage the development of brain tumour patient organisations’ conferences.

Denis (IBTA Chair) and Kathy (IBTA Co-Directors) are frequent plenary and session speakers at conferences, putting forward the patient viewpoint and raising awareness of the particular challenges which brain tumour patients face.

The IBTA also makes submissions to relevant regulatory body inquiries and is involved with broader patient and scientific bodies e.g. European activities in relation to rare cancers such as the European Society for Medical Oncology (ESMO) Action Against Rare Cancers and the European Cancer Patient Coalition’s (ECPC) Action Group on Rare Cancers.

The IBTA is a completely voluntary organisation and neither of the two Co-Directors nor any of the advisors are remunerated. Denis and Kathy are assisted in their work by importer Chris Tse from Wellington, New Zealand, in his Taipei office.

IBTA advisor Chris Tse from Wellington, New Zealand, in his Taipei office.

To estimate the annual worldwide incidence of primary malignant brain tumours (200,000 is the estimate), to promote its annual projects and to convey a patient and caregiver perspective, where possible, the IBTA attends and exhibits at the key scientific conferences relevant to the brain tumour community, including the American Society of Clinical Oncology (ASCO), European Association of Neuro Oncology (EANO), European CanCer Organisation (ECOC)/European Society for Medical Oncology (ESMO), British Neuro Oncology Society (BNOIS), and Society for Neuro Oncology (SNO) conferences. Additionally, the IBTA has exhibited at the UICC World Cancer Conference and national brain tumour organisations’ conferences.

IBTA advisor Sally Payne represented the IBTA at the 2008 ASCO conference in Chicago, and was assisted by local couple Eileen and Seamus Feely (unfortunately Seamus later passed away from his brain tumour).

IBTA advisor Chris Tse from Wellington, New Zealand, in his Taipei office.

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The Foundation Meeting

2005 - Then and Now

6, 4) Maureen Daniels and Rosemary Cashman (Canadian Alliance of Brain Tumour Organisations)
Maureen Daniels continues as the coordinator at the Pencer Brain Tumour Centre at Princess Margaret Hospital, Toronto. Rosemary later moved to the British Columbia Cancer Agency where she produces the very informative “Headlines” newsletter for brain tumour patients and their families.

33) Professor Geoff Pilkington
(Professor of Cellular and Molecular Neuro-Oncology at the University of Portsmouth and continues to play an important role in neuro oncology research in the UK.

28) Dr Rakesh Jalali
(Brain Tumour Foundation of India) Dr Jalali continues to oversee the BTF while working at the Tata Memorial Hospital, Mumbai, India. He has organised activities at the Hospital in conjunction with the IBTA’s International Brain Tumour Awareness Week. Rakesh is also a founding member of the Indian Society of Neuro-Oncology.

1) Alan Gow
(Macmillan Cancer Support, UK) Alan keeps in contact with the IBTA and is still a key organiser in Scotland for the Macmillan organisation.

21) Judy Gordon

11, 13) Kevin and Marguerite Sculc (Virginia, USA) To our sorrow, Marguerite passed away on 29 September 2009 after a courageous battle against her brain tumour but not before establishing a patient support group in Virginia (USA) and arranging for assistance to be provided to the Zimbabwe Brain Tumor Association.

24, 25) Mike and Dianne Traynor
(Pediatric Brain Tumour Foundation, USA) Mike Traynor passed away on 12 September 2009 after a short illness. His wife and co-founder Dianne has assumed the role of President and Chairman of the Board of the PBTF.

Professor John Darling
(Wolverhampton, UK) John is particularly interested in the molecular cell biology of human malignant brain tumours. John is now Dean of School of Applied Sciences and Director of the Research Institute in Healthcare Science (RiHS) at the School of Applied Sciences, University of Wolverhampton, UK.

Dennis Roth
(The Brain Tumor Society, USA) Dennis died unexpectedly in May 2007 after attending a brain tumour fund raising activity in Washington DC. The Brain Tumor Society, of which he was Chair joined the National Brain Tumor Foundation on 30 June 2008 to become the National Brain Tumor Society.

29) Ibrahim Qaddoumi
(Jordan) Dr Qaddoumi later transferred to the St. Jude Children’s Research Hospital in Memphis, Tennessee, where he is the Director of Telemedicine in the International Outreach Program.

Virginia Stark-Vance
(Author of “100 Questions and Answers about Brain Tumours”, USA) It was at the WFNO conference that Dr Stark-Vance gave early results of her experimentation with Avastin for brain tumours. She and her co-author M.L Dubay have now produced a second edition of their popular book (see later in the magazine).

3) Dr Jun Takahashi
(Kyoto, Japan) Dr Takahashi re-established contact with the IBTA at the WFNO meeting held at Yokohama in 2009.

2) Dr Mitsuaki Shirahata
(Kyoto, Japan) Dr Shirahata works at the Department of Neurosurgery, Kyoto University Graduate School of Medicine, Japan, and has published on gene expression in brain tumours.

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18) Zoe Hoppe
(formerly with the UK Brain Tumor Society, now Brain Tumor UK) Zoe Hoppe retired from her position as Chief Executive Officer of Brain Tumor UK in September 2005.

7) Dr Yutaka Sawamura
(Neurosurgeon, Japan) Dr Sawamura continues to work at Hokkaido University School of Medicine, Sapporo, Japan, and met up again with the IBTA at the WFNO conference held at Yokohama in 2009.

16) Angela and Neil Dickson
(Directors, Samantha Dickson Brain Tumor Trust, UK) Neil and Angela continue their energetic work at the “Samantha Dickson Brain Tumor Trust”.

Hanneke Zwinkels
(The Netherlands) Hanneke is an advance nurse practitioner in The Hague, Netherlands, and in 2009 wrote an important article about the role of the neuro oncology nurse.

Sharon Lamb
(USA) Sharon has been a strong supporter of the IBTA from the very first day. She volunteers one day a week at the National Brain Tumor Society in San Francisco. Sharon is a board member of the NIBTS and is a Director of the Ben and Catherine Ivy Foundation.

14, 12, 31) Mary Hogan, Joan Wynne and Mary O’Leighthen
(Brain Tumour Support Group, Ireland)

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14, 12, 31) Mary Hogan, Joan Wynne and Mary O’Leighthen
(Brain Tumour Support Group, Ireland)
The Walk Around the World for Brain Tumours

After three years of walking around the world for brain tumours, supporters amass enough miles to go to the moon and half way back!

People of all ages who set out to raise awareness of and funding for brain tumour research and support have not only encircled the globe 14 times with sponsored walks but have achieved the kilometric equivalent of a trip to the Moon and halfway back.

From America to Zimbabwe, and places in between, patients, caregivers, medical professionals, researchers, scientists and others with an interest in this disease put on their walking shoes to participate in the international effort to raise awareness of the challenges of brain tumours, one of the most devastating of all cancers.


“The idea behind the World Walk is simple,” said Mr Denis Strangman, Chair of the International Brain Tumour Alliance (IBTA, a not-for-profit voluntary organization).

“Individuals and groups take part in sponsored walks. Funds raised go to local brain tumour research projects or patient/caregiver support initiatives. The walking mileage achieved during the walks is symbolically ‘donated’ to the IBTA and is set against a target total of walking the distance around the world at the Equator.”

In 2007, the target was once around the world at the Equator – a distance of 25,000 miles (or 40,000 kilometres). In 2008, the target was three times the equivalent of a trip to the Moon and halfway back again!

In 2009, the target was five times around the world at the Equator – a distance of 75,000 miles or 120,000 kilometres. And in 2009, the target was five times around the world or 125,000 miles (200,000 kilometres).

The total walking mileage achieved over the last three years is a staggering 563,845 kilometres (350,357 miles), which is the equivalent of not only 14 times around the world at the Equator but the equivalent of a trip to the Moon and halfway back again!

Mr Strangman added: “Not only do these walks help raise desperately-needed funds for more research and better support, but the World Walk unites all those around the globe whose lives have been touched by a brain tumour.”

A number of walks were already in existence when the Walk Around the World for Brain Tumours began in 2007. These have now allied themselves to the World Walk by donating mileage. Other walks were initiated directly as a result of the IBTA’s promotion of the World Walk.

The IBTA also project-manages the International Brain Tumour Awareness Week which in 2010 will run from Sunday, 31st October to Saturday, 6th November.

In 2009, 182 brain tumour, neurological and cancer organizations around the world supported the “Week and Walk”.

Both the Week and the Walk generated publicity, fund raising, new initiatives and a sense of community. Throughout the pages of this magazine you will find examples of initiatives and a sense of community. Not only has man walked on the Moon, but thanks to the efforts of over 100,000 people around the world, man has symbolically walked to the Moon and halfway back to help achieve a better future for brain tumour patients.

World Walk Statistics *

Total over three years (2007, 2008, 2009):

People: 109,488
Walks: 275
Countries: a yearly average of walks in 20 countries
US $ equivalent raised: USD $14.6 million
Mileage achieved: 563,845 kms

* Some of the walks included in these statistics were already well-established by brain tumour organisations in various countries and they have kindly supported the IBTA’s Walk Around the World for Brain Tumours by donating walked mileage. Other walks were established as new events by those organisations who wished to support the World Walk by directly initiating this type of activity. None of the funds raised are given to the IBTA.

Levi’s Star Newmillerdam Walk

One hundred people took part in a sponsored walk around Newmillerdam (UK) in March 2009 and raised funds for Levi’s Star, a brain tumour charity established by Levi’s mum Vicky Ringer and grandmother Val Ringer, in honour of six year old Levi Ringer who died from a brain tumour in August 2006. The walk was approximately three miles around the dam and resulted in a contribution of 300 miles to the 2009 Walk Around the World target and thousands of pounds in donations to the charity. Val and Vicky also accumulated 730 miles for the World Walk target from a number of individual mileage donations.

For more information on how you can participate in the Walk Around the World for Brain Tumours and the International Brain Tumour Awareness Week, see the IBTA’s website at www.theibta.org or contact chair@theibta.org or kathy@theibta.org
**TREKKING KOKODA FOR A CURE**

By Sarah Mamalai

My name is Sarah Mamalai, I’m a 36-year-old mother of two young boys who was happily going along living my life in Australia until May of 2007 when I was diagnosed with an incurable and very aggressive cancer of the brain (Grade 4 glioblastoma multiforme - GBM and P-NET brain tumour within). Our life since then has been like riding the world’s biggest roller-coaster. 

I burst into tears as I was determined not to be carried...

Incredibly, among the lows there have been some amazing highs, the biggest of which was meeting Dr Charlie Teo. He is the neurosurgeon who performed the brave and brilliant surgery that saved my life and extended the time I have to share with my friends and family. After having two lots of major brain surgery, extensive radiotherapy and chemotherapy, one of my doctors suggested that I should set some goals. I felt I needed an extreme challenge to take my mind off the cancer so decided I would walk the Kokoda Track along with friends and family.

I contacted my dear friend, Ken Selu, from Nuigini Adventure Tours and asked for his help to achieve this seemingly impossible goal. At that point I had barely even been bush walking so this was a very challenging task! After five months of training, I completed the trek in eight days in May of 2008, one year after diagnosis. What an amazing trip and what amazing people we had along with us. When people ask me how it was I say incredibly - incredibly hard, incredibly rewarding and incredibly beautiful. I think the hardest day for me was day one when I realised exactly how tough it was going to be and the fear that I wouldn’t be able to complete the trek on my own two feet. I have serious balance problems and was over-compensating for my weaker left side by leaning like a banana on my right walking stick.

The porters said they wanted to carry me down the mountain. I burst into tears as I was determined not to be carried and they relented. My sticks were replaced by two amazing porters - one on each hand. And the rest is history!

My favourite day was the last day - the walk into Kokoda Station in the dark with all of my Kokoda OS team, being covered with frangipanis being thrown at us by the hiding villagers, fireflies in the night sky and to mark my entry into Kokoda an arch of walking sticks - AND it was the only truly flat bit of the whole walk! I could never have done it without Ken’s help. He also helped me raise AUD $50,000 in sponsorship for the Cure for Life Foundation, a cause very close to my heart. The Cure for Life Foundation was established by my neurosurgeon Dr Charlie Teo to help fund advancements in the treatment of brain cancers like mine, hopefully leading to a cure someday.

My favourite phrase is “You can weather the storm by dancing in the rain”. I have been rewarded for my dance and am still going strong nearly three years after my initial terrifying diagnosis.

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**WHAT IS THE KOKODA TRACK?**

The Kokoda Track is a single-file track that runs 96 kilometres (60 miles) overland through the Owen Stanley Range in Papua New Guinea. The track is the most famous in Papua New Guinea and is renowned as the location of the World War II battle between Japanese and Australian forces in 1942.

The gruelling track is popular with intrepid travellers. Rugged terrain, hot, humid days with intensely cold nights, torrential rainfall and the risk of tropical diseases such as malaria make it a challenge to walk.

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**Kick Biker With A Mission**

By Klaskoe Hofstee

I am President of Stichting STOPhersentumoren.nl which is a Dutch foundation with the mission to raise awareness of primary brain tumors and the effects of this disease. We also support independent (international) research and knowledge of primary brain tumors with the aim of curing the disease. My husband Nico Faasj and I founded the organization on September 5, 2007 and it has grown into a medium sized organization, number three on the Dutch list of donors to brain tumor research.

Never in my working life have I been president of a foundation. On July 20, 2007 my husband Nico, 38 years old, was diagnosed with an incurable malignant brain tumor. This showed up after an epileptic attack, I talk a lot with the people around me and especially with my husband Nico. I get tremendous daily enjoyment from our daughters Noa (six years) and Myrthe (four years). Luckily my work is not always sad news, although there are obviously very sad times too. The work I do gives me a lot of positive energy and keeps my job well balanced. I get the most satisfaction from achieving results such as raising money for brain tumour research and knowing that patients are happy with our work.

The biggest challenge of our work in the brain tumour community has been building our reputation, but also winning the recognition of other parties.

The first three items on my wish list for brain tumour patients would be:

1. hope – because cancer without hope is nothing to fight for;
2. improved survival and (3) better understanding for employers and caregivers that the effects of a brain tumor are very serious for the patient and also for his immediate surroundings.

To relax, I love to walk and I love gardening, so I can’t wait until spring comes and all the plants in my garden grow. I call this “garden therapy”, if I am busy gardening my kids help and play around me. That gives me much pleasure. Also I love to ride on my kick bike. That is a bike without saddle and pedals. I have set up an activity of climbing mountains in France called “Alpe d’Huez” with a kick bike. It is a great sport to do. You do not achieve as many kilometers as with a real bike before you feel tired, but you can achieve more kilometers than with running.
I am the President and Chairman of the Board of the Pediatric Brain Tumor Foundation as well as co-founder along with my husband Mike of this non-profit organization, I myself was diagnosed with cancer several years after my introduction to the disease of pediatric brain tumors. Experiencing cancer at a personal level, I grew to have a much greater empathy for the children and their families who were fighting pediatric brain tumors.

My husband and I became involved with pediatric brain tumors through a business colleague of my husband’s who had a child diagnosed with a medulloblastoma tumor at the age of five months. After watching that family’s struggles and after meeting other children and families dealing with the same disease Mike was led to do a fund raiser to support research. That was the beginning in 1984. Mike and I did this as volunteers for the first eight years while continuing our professional careers but in 1991 and after personally experiencing the deaths of five months. After watching that medulloblastoma tumor at the age of five months. After watching that family’s struggles and after meeting other children and families dealing with the same disease Mike was led to do a fund raiser to support research. That was the beginning in 1984. Mike and I did this as volunteers for the first eight years while continuing our professional careers but in 1991 and after personally experiencing the deaths of another child and families dealing with the same disease Mike was led to do a fund raiser to support research. That was the beginning in 1984. Mike and I did this as volunteers for the first eight years while continuing our professional careers but in 1991 and after personally experiencing the deaths of another child...
What are saucers for?

By Denis Strangman
Reproduced with kind permission from “The Way Ahead Update 3”.

Caring for someone with a malignant primary brain tumour can be a very challenging task.

Unlike other cancers, brain tumours are the only cancer to affect both a person’s mental and physical characteristics.

The patient and carer’s journey is not one that has been chosen voluntarily. You have no satellite navigation to guide you and signposts are few and far between. While major steps have been taken since around 2000 in developing new medical therapies for patients with a brain tumour, there is no ‘cure’ at this stage and that fact is always at the back of the carer’s mind.

When my wife of 26 years was diagnosed in her 50s with a glioblastoma multiforme brain tumour, I started locating useful information such as the Primer booklet published by the American Brain Tumor Association (see http://www.abta.org/) and distributing it to others who were in a similar situation. I also became a ‘brain tumour patient advocate’ following my wife’s death just eleven months after her initial diagnosis.

Our brain tumour journey commenced four years after my retirement from a very busy career. My wife and I had raised five children together and we had experienced all the ups and downs and tribulations of family life. We did have a common view about an afterlife and I believe this helped. My new ‘employment’ was now to look after my wife full-time.

To reach out to other people, I established a web diary of our journey and kept friends and relatives informed of my wife’s progress. It also led to new contacts who were also making this journey. My wife checked entries in her diary, called Mang’s Journey, before they were uploaded. The diary is still there and can be accessed at: www.ozbraintumour.org/Journey.htm.

My wife developed an attitude of ‘realistic hope’ as her guiding star... you may have more quality time with the person for whom you are caring.

My wife developed an attitude of ‘realistic hope’ as her guiding star - if she was to be the one who was cured, who experienced a miracle, or had a lengthy survival, then that would be great but she did not lose sight of the unfortunate prognosis that this type of disease has. A person’s interpretation of ‘hope’ will vary immensely. To outsiders their view might be totally unrealistic. The important thing is not to destroy that hope because it might be the only buoyancy vest that is keeping them afloat. My wife’s adoption of ‘realistic hope’ made it easier for us to talk about issues that many couples do not usually discuss, e.g. having a will, the power of attorney, what to say to the medical staff if she required resuscitation, etc.

It was only later that I discovered the concept of ‘anticipatory grief’. Had I known about it earlier my frustration and anger might have been more easily understood.

Anticipatory grief is a process in which you can experience the stages of grief - anger, depression, sadness, etc. - before the passing of your loved one actually occurs. Patients can also grieve about what they foresee their future to be, or how their partner might cope. Being alert to mood changes and their possible cause is useful advice for all full-time carers, but do not neglect your own physical health.

As my wife’s illness progressed she found it difficult to multi-task and I became the chief cook and bottle washer in the home. I admit that what we ate was what was convenient to buy and to cook. If it looked good on the frozen food package then that would be our meal. Naturally, ice cream, chocolate, cakes and pastries always look good and convenient and how could we deny ourselves some ‘comfort food’? I later paid the price with the emergence of type II diabetes, brought about, so my doctor said, by poor diet while being a carer, lack of exercise and stress.

If I have one piece of advice to pass on to fellow carers it is this: learn to restrain yourself when you are tempted to step in and do something for your loved one when they are still capable of doing it. Who cares if a cup of tea overflows into the saucer when being poured from the teapot. That’s what saucers are for isn’t it?

Mang Strangman

A proud father of the bride: Denis Strangman and his wife Josephine at the wedding of his daughter Josephine and her husband Drago in 2009.
The Association IRENE Onlus was created in 2005 by brain tumor patients and their families with the aim of promoting better knowledge and quality of care for patients and caregivers.

In the last years IRENE Onlus has supported home care assistance for brain tumor patients discharged from the National Cancer Institute Regina Elena in Rome, Italy.

IRENE’s fundraising allows the delivery of rehabilitation at home, as well as cognitive training, psychological support and social worker assistance for patients and caregivers.

A web site (www.associazioneirene.it) has been created to provide information about the disease and patients’ rights, and to answer patients’ questions.

Since 2007, IRENE has participated in the IBTA International Brain Tumor Awareness Week, organizing the walk “Corri al Massimo per IRENE” in memory of Massimo Crocco, a runner who died some years ago from a brain tumor.

Each year hundreds of people - patients, families and friends – take part in the 5 km walk, held in a beautiful park in Rome named Villa Pamphilj.

ASSOCIAZIONE IRENE ONLUS
L’associazione IRENE Onlus è stata fondata alcuni anni fa per iniziativa di pazienti e familiari di persone affette da tumori cerebrali. Obiettivo dell’Associazione IRENE Onlus è quello di aiutare le persone che hanno ricevuto una diagnosi di tumore cerebrale e i loro familiari ad affrontare i problemi sia di natura sanitaria che psicologica e sociale che questa diagnosi comporta.

L’Associazione IRENE Onlus ha contribuito con la sua attività a promuovere l’assistenza domiciliare per malati neuro-oncologici dimessi dall’Istituto Regina Elena raccogliendo fondi destinati a migliorare la qualità dell’assistenza ai malati.

Il sito web all’indirizzo: www.associazioneirene.it fornisce ai pazienti e alle famiglie informazioni sulla malattia, sul l’accesso ai diversi trattamenti e ai diritti del malato.

L’attività di IRENE Onlus si basa sul contributo diretto di pazienti e dei loro familiari per sostenere alcuni progetti già attivi e nella realizzazione di nuovi obiettivi come:

- Facilitare l’accesso alle prestazioni socio-sanitarie, informazione e supporto per facilitare il disbrigo di pratiche burocratiche (invalidità civile, inabilità, legge 104, congedi lavorativi), richieste di presidi sanitari, invio al domicilio di “assistenti alla Persona”
- Riabilitazione: attivazione di neuro-riabilitazione motoria, terapia del linguaggio e riabilitazione cognitiva a domicilio
- Informazione: aiutare le famiglie ad assistere consapevolmente i propri cari attraverso l’attivazione di servizi di informazione ed educazione
- Assistenza psicologica: assistenza al malato, ai familiari e consulenze di terapia familiare
- Formazione del personale medico e paramedico sulle tematiche della neuro-oncologia e della psiconcologia (corse di studio, aggiornamenti)

L’Associazione IRENE Onlus ha partecipato dal 2007 alla settimana internazionale sui tumori cerebrali promossa dall’IBTA organizzando una corsa podistica dedicata alla memoria di Massimo Crocco uno sportivo scomparso per tumore cerebrale. La corsa si intitola “corri al massimo per IRENE”. Alcune centinaia di persone hanno partecipato alle tre edizioni della corsa di 5 km che si è tenuta nel parco Villa Pamphilj di Roma.

The biggest challenge of my work in the brain tumor community has been the effort needed to elevate and keep the brain tumor cause in the national spotlight.

The first three items on my wish list for brain tumor patients would be (1) successful treatments, (2) safe treatments and (3) peace of mind. When it comes to relaxing outside of the office, I enjoy spending time with my husband and family. I practice yoga and read historical biographies, but when I really need a distraction, it’s to the couch with a blanket, fire and a movie, preferably a romantic comedy, any era!

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In the world of oncology
Combination is key

CIRO SCERONI ONCOLOGY
combines approaches that target

Merk Scerono Oncology combines approaches that target

Tumor cell
Tumor environment
Immune system

to optimize therapeutic success

By Elizabeth Wilson
Executive Director, American Brain Tumor Association (ABTA)

I am the Executive Director of the American Brain Tumor Association. I have worked in national non-profit marketing and strategic management for most of my career including for such organizations as the American Hospital Association, Alzheimer’s Association and National Safety Council.

I’ve known since very early on in my career that my skills, personality and drive for professional and personal fulfillment were well suited to the non profit world and “causes”.

I’ve always had a tremendous amount of energy and am able to draw from it to push through difficult times.

I also take the time to restore my emotional and intellectual reserves. I try to keep positive and maintain a sense of humor.

What gives me the most satisfaction from my work is knowing how this one organization is having a tremendous impact on the lives of so many individuals and families. It is truly humbling.

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ROC ON, LAURIE!

By Laurie Dangler, MD
Doctor, organiser of the “ROC on” brain tumour running/walking team, brain tumour survivor (United States)

My brain tumor was diagnosed after my first surgery as “oligodendrocytoma”; I sought a second opinion at a well-known hospital and they diagnosed it as “anaplastic astrocytoma”. I was originally seen by a neuro- oncologist who did not appear to know how to treat me and who used an inappropriate manner to say “It’s gonna’ kill you” to me three times in a row when I was still in the hospital recovering from my first surgery. I found a new oncologist as soon as I could!

The diagnosis of brain cancer affected my life greatly, especially as I was given a prognosis of five to seven years to live. I look at life very differently now when I feel I have much less of it left to live than what I had expected. I was 37 years old and my children were six and eight years old when I was diagnosed. I fear that I will not see them graduate from school, get married, or have children of their own. I feel I am more likely to voice my opinion after my first surgery as my brain tumor was diagnosed. I started a team called “ROC on!” (Run Over Cancer) in the first year after my diagnosis which runs and walks in many different races throughout the year. The goals of “ROC on!” are: (1) to increase the public’s awareness of the mortality caused by brain cancer, (2) to raise money to help support research to find a cure for brain cancer, and (3) to help support patients and their families in their diagnosis and treatment of brain cancer. Organizing the “ROC on!” team has helped me get additional support from my employer, patients and co-workers.

I attend a brain tumor support group meeting that is held on a monthly basis in Columbus, Ohio and I have met many people with brain tumors and brain cancer at the meetings as well as the university’s yearly Brain Tumor Survival Celebration Event. I will often call or e-mail newly diagnosed patients to help them answer any questions they have about their diagnosis.

Regarding tips to the newly diagnosed - live life to the fullest and be positive about the good things you have in your life. Do not concentrate on the statistics involved with your brain tumor - expect that you can outlive the prognosis given to you. Make a “bucket” list of the things you most want to do before you die and do what you can to do those things.

The first three things on my wish list in relation to this disease are: (1) to find a cure in time to help me survive; (2) to hold on to my good health for as long as possible and (3) to show others how short one’s life can be and that we all need to appreciate the good things we have.

To relax, I play music and use my running as stress relief. •

[Editors’ note: For more information on the “ROC on!” team see www.roconnow.com There is also a ROC on! contact on Facebook.]
By Anso Thom, Health Writer,
Health-e South Africa (http://www.health-e.org.za)

African countries that had introduced palliative care with access to morphine possible include Zimbabwe, South Africa, Kenya, Uganda, Tanzania, Malawi, Nigeria and Cameroon - 32 African countries have almost no access at all to oral morphine. Merriman identified the main barriers to access as the low priority afforded to pain management in health care systems, greatly exaggerated fear of addiction, severe "morphinephobia", inadequate knowledge about morphine and overly restrictive laws governing the use of narcotics.

A note from the Editors

For these reasons we encourage members of the international brain tumour community to become more deeply involved in the palliative care movement so that brain tumour patients at the end of life stage will benefit from a more generalized improvement in palliative care in these countries. A good starting point is the International Association for Hospice and Palliative Care (http://www.hospicecare.com/)

One encouraging development in trying to document the experiences of terminally-ill brain tumour patients in these countries and their specific needs for morphine for pain control, dexamethasone (or alternatives) for brain swelling, and anti-convulsant medications for seizure control. Agencies such as Médecins Sans Frontières (MSF) have only been able to tell us that brain tumour patients are usually unrecognized specifically within primitive health centres, would be diagnosed late if at all and do not receive what we would regard as the standard of care.

As far as the IBTA is aware the facts in Anso Thom’s article are accurate, however, we are unfamiliar with the background behind the suggestion that an orthodox religion in Ethiopia endorses suffering as a way “to get to heaven”. Also, while the USA might be a high user of morphine per capita, it is Austria that actually tops the world tables. Be that as it may, the situation in many African and less developed countries is dreadful as far as palliative care is concerned. For several years the IBTA has been trying to document the experiences of terminally-ill brain tumour patients in these countries and their specific needs for morphine for pain control, dexamethasone (or alternatives) for brain swelling, and anti-convulsant medications for seizure control. Agencies such as Médecins Sans Frontières (MSF) have only been able to tell us that brain tumour patients are usually unrecognized specifically within primitive health centres, would be diagnosed late if at all and do not receive what we would regard as the standard of care.

Dr Merriman shared the story of a 24-year-old dying man who had to travel to hospital every day on the back of his son’s bicycle - simply to get pain medication. If Merriman is the mother of palliative care in Africa, Ugandan doctor Jagwe is described as the father. He said it was "miserable and pathetic" that only 23 of 154 countries were above the global average when it came to access to pain medication.

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By Jenny Baker
Chief Executive Officer, BRAIN TUMOUR UK

I am the Chief Executive of Brain Tumour UK for four years, following some thirty years of previous voluntary and community sector experience. In 2004, I lost my eldest son Stephen to a brain tumour. He was just 24, so I know personally how devastating a diagnosis can be.

When this role at Brain Tumour UK came up, I felt I could offer help to others along their brain tumour journeys. My first discovery was how diverse brain tumours are. So we’ve worked hard to reach out to previously neglected groups, including those affected by so called “benign” tumours, such as meningioma, and by secondary cancer in the brain.

Emotionally, it’s a very challenging role and running a large charity with major financial commitments is demanding in the current financial climate. Yet despite that, I am constantly inspired by the patients and families we support. It’s humbling to see how often people respond with quiet courage and resilience to a diagnosis. My admiration for many nurses and other healthcare professionals is boundless, I find it easier to cope with pressure because I am not alone and that is our message to those that we support, too.

What gives me the most satisfaction from my work? For me, it’s the support that we provide. Of course the research that we fund is vital and we’ve made great headway in raising awareness. But people diagnosed today need support right now. With regard to challenges in this work, I’ve always advocated that charities achieve more by working together. That can be hard – in the real world, charities often see one another as rivals – so I have strived to encourage partnerships.

The first three items on my wish list for brain tumour patients would be:

1) removing the postcode lottery of care for patients. The official standards laid down by the National Institute for Health and Clinical Excellence (NICE) for caring for people with brain tumours should be fully implemented in England, and to the same level in Northern Ireland, Scotland and Wales;

2) improved early diagnosis for both children and adults, with better support to help GPs and others spot critical symptoms sooner;

3) new treatments for brain tumours, through more coordinated and better-funded research. We’re making real progress in this area, but there is so much more to be done.

By Giovanni Camporeale
SCIENTIST, PATIENT ADVOCATE AND DEVOTED CAREGIVER

I am the co-founder of BrainLife.org [based in Italy], a website that collects sources of and references to the latest published medical sources in the field of brain (and other CNS) tumor research and treatment. The other co-founder is my wife Elisabetta, who is a GBM survivor diagnosed in 1999. Elisabetta is also the honorary president of the Italian brain tumor association “Il fondo di Gio”, where I am a member of the Scientific Committee (http://www.ilfondodigio.it/),.

I write neuro-oncology articles for the Italian and the English Wikipedia. My wife and I have significant correspondence with brain tumor patients and caregivers. Elisabetta is on Facebook too.

I started to collect brain tumor articles in 1999. The first brain tumor (BT) site was called “Glioblastoma Database and Newsletter”. Elisabetta and I founded Brainlife.org in 2003.

I am the caregiver of my wife. As for many others, my initial will was to understand. I read articles to understand. I was in touch with many other people who convinced me to re-publish the references and sources. They have been regularly updated as has my knowledge. The work for the BT association started later.

I am a physicist. My mental state and training requires me to be curious. I grip topics like a determined mastiff and won’t let go easily! I will only stop my work when a stable solution is found to the brain tumour question. The replies from patients and caregivers give me the most satisfaction from my work.

The biggest challenge of my work for brain tumor patients would be: (1) a doctor who cares for your BT problem; (2) a strong will to fight and (3) a cure for these most terrible brain tumours. To relax, I like to read and listen to classical music.

The first three items on my wish list for brain tumor patients would be:

1) increased funding for research so that we can advance treatments and ultimately find a cure; (2) earlier diagnosis and (3) readily accessible information in a user friendly format.

Outside of work I enjoy relaxing over a glass of wine, sunbathing and watching Disney DVDs with my children.

THE DREAM TEAM

By Sue Farrington Smith
Director of Brain Tumour Research/Trustee of Ali’s Dream

I am the Director of Brain Tumour Research and Trustee of Ali’s Dream in the UK, which raises funds for childhood brain tumour research. Along with family and friends we founded the charity Ali’s Dream in June 2003 following the loss of my sister’s little girl Alison Phelan three weeks before her eighth birthday. We joined forces with other brain tumour charities in 2003 to form the United Brain Tumour Campaign and in 2008 we formalised the group under the umbrella of ‘Brain Tumour Research’. We launched Brain Tumour Research at the House of Commons in April 2009.

The loss of my beloved niece Alison Phelan to a brain stem glioma, and the horror of discovering how little research there is into brain tumours inspired me to become involved in this work. Ali is the inspiration behind everything I do and the other families that we have met along the way provide the motivation to keep going. I have a clear focus on our aims to raise £7million pounds per year to fund research at seven centres of excellence in the UK. I do not get involved in anything that would distract me from this and which does not have a clear purpose.

What gives me the most satisfaction from my work? Feeling the loyalty that there is amongst the members of Brain Tumour Research, seeing the funds increase and planning how we can support UK brain tumour scientists with their research.

The biggest challenge is engaging people to work together and stay together. We have achieved this through having a common vision and a common ethos.

The first three items on my wish list for brain tumour patients would be: (1) increased funding for research so that we can advance treatments and ultimately find a cure; (2) earlier diagnosis and (3) readily accessible information in a user friendly format.

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Mo Mowlam Survey

Initial Overview for the IBTA Prepared by Jackie Weaver

Over 350 people participated in an IBTA survey based around the story of former United Kingdom Parliamentary Minister Mo Mowlam who had a malignant brain tumour and told the then Prime Minister Tony Blair it “didn’t really matter”. The IBTA invited Jackie Weaver, who has an MSc in Social Research Methods and Statistics and over twenty years’ experience in social and market research, to prepare a summary of the initial de-identified data (93 pages) and to outline what the answers reveal. Two members of Jackie’s immediate family had brain tumours so she brings to the task both a professional and personal interest. Do brain tumour specialists have a different impression of how their patients will be viewed in the real world? Read the analysis below.

The background conveyed to those who were surveyed

Background: Mo Mowlam was a Minister of State in the UK who was diagnosed in 1997 with a malignant brain tumour. She told the then UK Prime Minister Tony Blair that it was “benign” and “treatable”. She was appointed Northern Ireland Secretary and secured Unionist and Republican support for the 1998 Good Friday peace agreement. She died on 19 August 2005. A new television drama about her life reveals that she had a malignant brain tumour but she insisted on that fact being kept confidential. Dr Glaser has now informed of any problems this might bring to light, and recommending that they inform their superiors, and, or cease working, if they felt this was necessary.

The remaining respondents (219 in total) were based outside the UK. We have attempted here to give an idea of some of the differences between the groups. But of course, in some cases the sub-samples are very small, and the findings are indicative only. A more complete analysis, using the final sample of 368, will be conducted at a later stage. This will focus on the comments made by respondents, and some of the issues these raise.

What would they do if they were the patient in this situation? The patients were fairly evenly divided between those who said they would disclose the true nature of their illness, and those who would keep quiet. In the case of carers, there was a roughly equal three-way split, between those who would opt for disclosure, those who would keep their condition secret, and those who acknowledged that, while they might not have followed the same course as Mo Mowlam and (or) did not feel they were in a position to put themselves in her shoes, they completely respected her right to make her own decision.

A different pattern

The pattern was different among oncologists and neuro-oncologists. Those who volunteered an opinion on this were twice as likely to say that they would be honest about the nature of their illness than to say they would keep quiet about it. However, around half of both oncologists and neuro-oncologists (Subscribers to just over half of oncologists and neuro-oncologists) was to say that, while patient confidentiality should be observed, it should be subject to certain provisos. These included the patient’s own ability to make decisions, and the likelihood of their putting other people in danger (something which, it was acknowledged, would be much more difficult to pin down in this situation than if, for example, the patient were a surgeon or an airline pilot). Others pointed out that it could be difficult to judge the precise level and nature of cognitive impairment, if any, as the disease progressed, and several said they would arrange for neuropsychological testing if this was a concern, keeping the patient fully

Mo Mowlam Survey

No easy answers

In almost all cases, respondents’ comments revealed a strong awareness that this was a very complex dilemma, and that there could be no easy answers. Some of the issues that were raised and discussed were:

• the rights of patients versus the responsibilities of doctors
• the special problems of brain tumour patients
• problems with using terms such as ‘benign’ and ‘malignant’
• difficulties in establishing the nature and level of cognitive impairment
• the stigma which still exists, and the lack of understanding from others which is often experienced by patients.

Mo Mowlam’s particular situation – her rights as an individual with a brain tumour, versus her responsibilities as a public figure

A few said they would consult their hospital ethics committee, and just a handful felt that, if the patient insisted on keeping their condition secret, they would have no option but to withdraw from their care.

In the case of the other groups:

• Neurosurgeons, neurologists and allied health workers were roughly equally divided between those who felt that complete confidentiality should be observed regardless of other factors, and those who qualified this with the provisos discussed above.

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Malignant glioma - A perspective
by Professor Roy Rampling
Beatson West of Scotland Cancer Centre, UK

Oncologists can sometimes be guilty of understating what has been achieved in patient care. In 1978 Professor Michael Walker and colleagues published a seminal paper in neuro-oncology demonstrating the value of radiation therapy in the management of malignant glioma.

Nine years later, when I started in the discipline, still very few patients were referred for such treatment, and referrals were on an ad hoc basis. Their median survival was around six months with no one alive at two years. I saw patients in a single-handed clinic held one afternoon a fortnight.

In contrast in 2005 when Dr Roger Stupp and colleagues in the EORTC demonstrated the value of chemotherapy in glioblastoma the regime became standard practice throughout in the next few years the drug was approved.

In my unit this work now occupies three clinics every week and involves three doctors, three specialist nurses and radiographers and has access to psychology, physiotherapy and speech and language support. Median survival is around 18 months and 15% of patients are alive at four years. We should be proud of our progress in such a formidable disease.

What have we learned in this time? Well, perhaps the most important lesson is that persistence can pay.

The last 30 years have seen an explosion in our understanding of the cellular processes that regulate the growth and replication of cells and the genetic changes that occur when they undergo malignant transformation. Increasingly we understand how these genes are controlled and how the gene expression products interact within the diseased cell. This understanding will lead to opportunities either to re-route the cellular processes or to rectify the damaged cellular processes.

At the moment our efforts at this are crude. We have attempted to block one aberration at a time, for example the overactive EGFR receptor on the tumour cell surface or the excessive angiogenesis driven by the VEGF family. While no one would claim massive success from this approach neither is there any doubt that some patients do respond. Enthusiasm is such that at least two global phase three studies are examining the addition of single agents of this type to the standard treatment in newly diagnosed glioblastoma.

This discipline is at the same stage that cytotoxic chemotherapy was 30 years ago. The next 30 will see new generations of drugs used in combination to eliminate or rectify cancer damaged cells.

Cell cycle active agents are not the only novel anti-glioma developments to emerge from fundamental science. Research into DNA damage repair has delivered agents such as PARPis that can selectively enhance the killing of glioma cells by conventional DNA damaging agents such as radiation and temozolomide. New generations of anti-glioma vaccines are being studied which have the potential to enhance the body’s natural immune system and direct it against the tumour.

Novel viruses have been made that can selectively seek out glioma cells either to kill them directly or deliver a cytotoxic payload. These and other novel approaches hold significant promise for the future.

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Leading a Spirited Fight against Brain Tumors

By Christine Mungoshi
Director, Zimbabwe Brain Tumor Association

November 4th 2009 saw the Zimbabwe Brain Tumor Association hold its Walk Around the World for Brain Tumours in Harare. Altogether, 180 people walked 4.5 kms each, making a total of 810 kms denoted to the World Walk. A special celebration took place on the same day – the handover of an ultrasound scanner that had been donated to the Pairenyatwa Hospital by a UK hospital. During the ceremony, Esteri Chekeche, former carer to her young son Jerrold (who tragically passed away from a pediatric brain tumor) told of the anguished journey that she and her family embarked upon when Jerrold was diagnosed. Christine Mungoshi, Director of the Zimbabwe Brain Tumor Association, takes up the story.

A glimmer of hope
People of Harare whose lives had been touched by a brain tumor shared in an exciting but highly emotional celebration when they witnessed the arrival of a consignment of hospital equipment last November which included an ultrasound scanner. Thanks to the help of neurosurgeon Professor Garth Cruckshank of Queen Elizabeth Hospital and the Co-Director of the International Brain Tumour Alliance (IBTA), Kathy Oliver, we managed to arrange for this much-needed ultrasound scanner to be sent to Zimbabwe. This machine will make a great difference to the current situation in the Pairenyatwa Hospital in Harare.

The arrival of this machine brought a glimmer of hope to the patients awaiting treatment, especially children. The machine will make a difference to the outcome of pediatric surgeries. While this is good news for others, it comes too late for young Jerrold Chazika who lost his battle with a brain tumor nine months earlier. A bubbly seven year old, Jerrold succumbed to his brain tumor in such a painful way because he never had the chance to get the treatment that his parents so desperately sought for him.

At our handover ceremony on 4th November, Esteri Chekeche gave a detailed account of her son Jerrold’s journey with a brain tumor. It was a painful account. You could touch her pain. Esteri’s voice quivered with emotion and her eyes were foggy with tears while she poured out the pain in her heart.

As the delegates listened, the room became quiet and you could hear a pin drop. Most of them were choking with emotion, a few shed a tear. It was clear they were visibly moved. For many in the room, this was not a unique experience for they had either seen a worse situation or gone through an equally touching ordeal themselves. For many Esteri’s story brought to the surface their own concealed anguish.

Remembering Jerrold
After Esteri finished telling Jerrold’s story, she was in tears. I was also in tears. I held her in my arms as she got down from the stage and for a moment we sank into our sadness. I too cried for my young daughter, Paida, who had also died from a brain tumor. I shed tears for Jerrold as I had known him and had grown to be so fond of him. He had an eager face which would beam with a shining smile each time we visited. Jerrold’s favourite food was fish, and we always made sure that we brought him some when we could. It was so exciting to see how he appreciated it and thanked us with a beaming smile.

It was tragic to see this lovely boy deteriorate. We helped wherever we could for him to have some procedures done. He endured all the pain of needles, CT Scans and MRI but just like many, he never got any further treatments such as radiotherapy and chemotherapy.

I met Esteri for the first time in hospital. What struck me most about her was her warm smile, despite her difficult situation. She had an eight day old baby and a son with a life threatening ailment, but she could continue to smile.

A few weeks later when they witnessed the arrival of a CT scanner that had been donated to the hospital, they were visibly moved. It was a painful account. You could touch her pain.

Esteri’s story brought to the surface their own concealed anguish.

The Zimbabwe Brain Tumor Association
The Zimbabwe Brain Tumor Association (ZBTA) came into being at the height of socio-economic problems in Zimbabwe. The health system collapsed and the general population faced untold suffering. But the neuro-oncology story would still largely remain untold.

Two months later, she was still in hospital with Jerrold and it was growing less likely that he was going to get any treatment at all. As Jerrold’s condition deteriorated, and she grew exhausted from staying in hospital with a small child, Esteri was forced to make the very hard decision of taking her desperately ill child home where he would be in a familiar environment.

It was a painful journey as she prepared Jerrold for the inevitable. He asked if he was going to die, and Esteri took her young son through that journey slowly until he said he knew he was going to die and he was no longer afraid to die.

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The pain and suffering of brain tumor patients in my country is far beyond any imagination.

The Zimbabwe Brain Tumor Association is growing, and doing much more through its expanding force of volunteers. Most of them have had direct experience of this disease and want to make a difference in the lives of those who are currently affected.

We believe that through hope and strength we will achieve the impossible.

Some of our greatest accomplishments to date have been awareness campaigns. In Zimbabwe, we have distributed more than 5000 pamphlets and more than 1000 books and publications on brain tumors.

These books were a donation from several brain tumor charities in the United Kingdom and the United States of America, particularly the National Brain Tumor Society. The donations came as a result of our plea through the International Brain Tumour Alliance (IBTA).

The IBTA and ZBTA have worked closely together. ZBTA’s Christine Mungoshi presents IBTA’s Kathy Oliver with a special sculpture by renowned Zimbabwean artist Dominic Benhura.
We also have a supplementary feeding scheme, whereby we provide food for parents from outside Harare who have accompanied their children to hospital here. Some of the parents stay for months. They do not have the means of getting or affording food from fast food outlets for such a long period of time. We also organise special food requests from the young patients. For those patients who are either outside of Zimbabwe's borders has been a challenge due to limited resources. The ZBTA and KidzCan paid for transport, the medical equipment for the child, and food for parents from outside Harare. "

Lack of specialists and equipment in Zimbabwe we only have four fully qualified, registered neurosurgeons for a population of 13 million, which is half the population of Australia. This was a great shock to us. We have a lot of challenges due to limited resources to support our projects, lack of equipment in the hospitals and also few specialists in our country who can treat brain tumors.

We have also engaged the Ministry of Health to try and do something about the scarcity of neurosurgeons in Zimbabwe. The ZBTA still faces a lot of challenges due to limited resources to support our projects, lack of equipment in the hospitals and also few specialists in our country who can treat brain tumors.

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LONG TERM SURVIVOR
ELISABETTA

By Elisabetta Camporeale
Co-Founder of BrainLife, brain tumour survivor (Italy)

My initial diagnosis (1999) was gliosarcoma. At the first recurrence (2000) the diagnosis was glioblastoma. At the second recurrence (2001) the diagnosis was glioblastoma. I had strong headaches, diplopia, vomiting, nausea, epileptic fits, fainting fits. Now I have hemianopsy and staggering.

I am the co-founder of BrainLife.org, a website that collects sources of and references to the latest published medical sources in the field of brain (and other CNS) tumor research and treatment. The other co-founder is my husband Giovanni. I am the Honorary President of the Italian brain tumor association “Il Fondo di Gio”, where Giovanni is member of the Scientific Committee (http://www.ilfondodigio.it/). Giovanni and I have a significant correspondence with brain tumor patients and caregivers. I am on Facebook too. (I also have two sons, two granddaughters, etc.) Now I am retired. I am lucky that I receive adequate support. I have been lucky to have also my husband as caregiver and doctors who cared for my problems. In my opinion, patients need more information and humanity.

My tip for newly diagnosed brain tumour patients would be: don’t stop fighting.

The first three things on my wish list in relation to this disease are: (1) a doctor who cares for your problem; (2) a strong will to fight; (3) a cure as soon as possible for these most terrible brain tumors.

I like reading and listening to classical music (Bach, Chopin, Handel, Vivaldi, Mozart, etc). I write nursery tales for the little [pediatric] patients (on BrainLife.org).

Action! Lights! Camera! Photographs!

Multimedia brain tumour awareness raising campaign in The Netherlands

Klaske Hofstee, President of Stichting STOPhersentumoren.nl which is a Dutch brain tumour foundation, has come up with some excellent awareness raising ideas.

“Project TV commercial”
Stichting STOPhersentumoren.nl has made a TV commercial to highlight the challenges of brain tumours.

In the Netherlands every year 1500 people are diagnosed with primary brain tumours and told there is no cure. “That must change!” said Klaske Hofstee. “Our television commercial is a metaphor, showing how a person’s life can be overtaken by a brain tumour. The tumour is symbolized by a huge white balloon that is getting bigger and bigger, more reckless and uncompromising, and squeezing away everything around it.” Below is a still from the TV commercial but to view the commercial in its entirety, go to: www.stophersentumoren.nl/nl/nieuws/ReclameFilm/

“Project Book”
Stichting STOPhersentumoren.nl has also created a very impressive book entitled “1500 Hoofdzaken” about increasing awareness and understanding of brain tumour patients and highlighting the need for more brain tumour research. The book delivers the very important message that much more funding is needed for brain tumour research.

“Our book gives you a unique glimpse into the lives of people affected by this disease,” said Klaske Hofstee. The photographer for the project has created penetrating, but respectful portraits of brain tumour patients. Klaske has added some powerful quotes. Together they paint an impressive picture of what having a brain tumour really means. “I hope that more and more support and understanding can be given to brain tumour patients,” said Klaske.

For more information on these two exciting projects, contact Klaske at k.w.hofstee@stophersentumoren.nl

Our television commercial is a metaphor, showing how a person’s life can be overtaken by a brain tumour.

A scene from the TV Commercial made by Stichting STOPhersentumoren.nl. To view the whole production follow this link: www.stophersentumoren.nl/nl/nieuws/ReclameFilm/
Students Supporting Brain Tumor Research (SSBTR) is a remarkable organization. The journey from May 2009 to February 2010 was an exciting learning experience for all. In 2002, the organization was founded by teacher Steve Glassman. He saw the organization as a means of helping to fight the number one cancer killer other than leukemia, brain tumors. Students Supporting Brain Tumor Research (SSBTR) was founded in 2002 after the devastating deaths of three Arizona (USA) high school students.

During the organization’s first year, US $7000 was raised, and a Walk-A-Thon at a local high school in Arizona attracted three hundred participants. The money was raised to various brain tumor research laboratories, including Arizona’s Barrow Neurological Institute, the Translational Genomic Research Institute, and Phoenix Children’s Hospital. The first Walk-A-Thon was a success. Little did the original student volunteers know that just nine years later, the project pioneered would raise over one million dollars.

Over the next few years, the organization grew incredibly. More students signed on to volunteer, more corporations became aware of SSBTR’s brain tumor and made charitable donations, and more people were educated about the topic of brain tumors, their high fatality rates, and the need to find a cure. The non-profit began to focus its efforts on not only raising funds and awareness for brain tumor research year-round, but also on the coordination and establishment of an annual Walk-A-Thon. The planning for the February 27, 2010 Walk-A-Thon in Phoenix began in May 2009. At this time, the five student Co-Chairs began the grant writing process. Sponsors quickly signed on to the cause with SSBTR’s Presenting Sponsors donating more than $10,000 each. Despite the economic downturn, SSBTR saw an increased result from its fundraising efforts in the early stages of the 2009 “walk-season”. As the summer months passed, and August approached, more students began to seek involvement, this time from the university level. Simultaneously, interest at the high school level peaked, paving the way for a collaboration between high school and college students.

With the growth in involvement came the need to make the move from a high school track to a university venue for the 9th annual Walk-A-Thon. After a series of meetings, discussions, and debates, it was decided that the 2010 walk would take place at Arizona State University.

Students at the university kept busy with logistics - determining an exact location; working with Student Government to obtain adequate funds; and organizing items such as stages, speakers, tables and chairs for the event.

Meanwhile, the high school student Co-Chairs - Mikaela Gibson, Jesse Higgins, Jayden Miller, Amelia Spinrad, and Roxie Goldberg - worked around the clock to hire bands and other entertainment; to reach out to elementary, middle, and high schools around the state of Arizona; to gather silent auction items; and to generate media attention and publicity through public relations efforts.

The opportunities provided to the high school co-chairs proved to be invaluable. Jesse Higgins, SSBTR 2010 Co-Chair and Entertainment Committee Chair, said: "The best thing about being part of SSBTR was learning how to become a leader and using those skills to help organize a successful walk." As Entertainment Committee Chair, Jesse actively sought out bands, interviewed them and, with help from his adult counterparts, drafted contracts for the bands to sign. The real life experience and directing, the student Co-Chairs, alongside their university and adult counterparts, ensured that all aspects of the day ran smoothly.

When the doors opened at eleven o’clock, a mass of supporters crowded into the venue. Opening ceremonies began with the always emotional "Survivors Pledge of Allegiance" and were then followed with the ceremonial "Survivor First Lap," when the brain tumor survivors and their families, along with the families of those who had been lost to brain tumors, made the first third-mile lap. The remainder of the day was filled with participants each walking two miles, bidding on tens of thousands of dollars’ worth of silent auction items, and listening to the music of six local bands.

At the conclusion of the day, the students and adults who had spent the past nine months planning and organizing the event, felt a sense of accomplishment and pride.

On February 27, more than 3,500 walkers participated, and more than $50,000 was raised, totaling more than $250,000 for the year, and nearly $1.4 million since the inception of the organization in 2002.

SSBTR is a remarkable organization. The opening ceremony of the SSBTR Phoenix Walk-A-Thon at Arizona State University.

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"The things that we did with SSBTR weren’t things I could have done in other places. SSBTR puts students like myself into a position of having the capacity to make a difference and feel like you’ve made a difference." 

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HELPING SWEDISH PATIENTS COPE WITH A BRAIN TUMOUR DIAGNOSIS

By Åse Rinman
Chairman of Svenska Hjärttumorforeningen (The Swedish Brain Tumor Association)

I am Chairman of Svenska Hjärttumorforeningen, the Swedish Brain Tumor Association. I have been doing this work since the start of the Association in March 2006. I was one of four bereaved spouses who founded the Association.

My husband was diagnosed with GBM in 1993 and died in 1996. I would have wanted the support and possibility to meet others in the same situation when we were in the midst of all the turmoil. We went to the States for second opinions when the tumour recurred. I came into contact with the American Brain Tumor Association and their support work. This served as a role model for me when we founded our Association.

For every person I can ease the burden for, even if just a milligram, it feels like the loss of my husband has served some sort of purpose. It feels like the loss of my husband still serves as a role model for me when we founded our Association and their support work. This served as a role model for me when we founded our Association.

The biggest challenge of my work in the brain tumor community has been the nihilistic viewpoint of the healthcare community in certain areas of Sweden which is horrible. The way they treat a person as a “diagnosis” rather than a human being is beyond understanding. This prevents them from catching up with promising developments in the field and it is a true challenge to get through to them.

My wish list for brain tumour patients includes a cure for GBM. Also, the best possible care and treatment for everybody regardless of where you live or how big your wallet is. Also a dedicated multidisciplinary team for every patient where the patient and their near relatives know who the treating doctor is and what would be the next step in treatment if necessary - performed in a prompt way without any unnecessary delays! How do I relax? Ahh, I have a summerhouse…do I have to say more? But I sail too and read and write as much as I can. And in a way, the chairmanship IS a sort of “hobby”. I work full time as a business developer for Medtech and run the chairmanship in my spare time.

FOCUSING ON FUND RAISING AND SUPPORT

By Paul Carbury
Chief Executive Officer, Samantha Dickson Brain Tumour Trust (UK)

I am CEO of Samantha Dickson Brain Tumour Trust (SDBTT). To date, we have funded world class research to the tune of £5 million. We also provide support to patients diagnosed with a brain tumour as well as their families and carers and we deliver a number of patient centred events across the UK.

I have been at SDBTT for over two years and I have been a Non-Executive Director with one of London’s largest Primary Care Trusts for three years.

I was initially attracted to the role at SDBTT as my mother died of a brain tumour eight years ago. This meant I was aware of the huge challenges that people living with brain tumours and their families face.

To help cope with the pressures that develop in this work, I try to keep focused on the task at hand. Nearly every day I hear of and meet people whose lives have been completely turned upside down by brain tumours: parents have lost children, or are caring for a very ill child, and families may have lost loved ones and friends.

Knowing that the work we fund has a very real and direct impact on the lives of the people I described above gives me the most satisfaction. We are very selective in the type of research that we support, and choose only the highest quality projects according to our stringent review process which involves experts in brain tumours from around the world. We are also pushing for more clinical trials and running a national campaign to promote early diagnosis. I am also very proud of the work we do in supporting brain tumour patients and their families.

Cancer is a vast field and receives a significant amount of funding, yet brain tumours, which now kill more adults under 40 and children than any other cancer, feel like a missed opportunity of the annual cancer spend. What is more, it also takes three times as long to diagnose a childhood brain tumour in the UK than it does in other European countries.

The first three items on my wish list for brain tumour patients would be: (1) more funding for research - in our recent grants round we have had over £7 million of requests from the scientific community which clearly shows there is a need and demand; (2) earlier diagnosis - our own research with over 300 brain tumour patients and their carers, supported this; we also found that one in four patients had to consult their GP four times and (3) better emotional care and practical support for patients and families.

To relax, I enjoy running whenever I can although it can be difficult to fit it in sometimes, with a young family and a busy job! I also enjoy music and relaxing with my family, whether at home or on trips away.
DIFFUSE INTRINSIC PONTINE GLIOMA: Collaboration is Leading to Change

By Dr Loice Swisher

“T’s been almost two years since Sam was diagnosed in December 2006. The only improvement that I’ve seen during this time is that we have this wonderful site!” (the DIPG Internet Yahoo support list and discussion group).

So said “Sheila” (in December 2008), whose young grandson had died in February 2008 from a diffuse intrinsic pontine glioma. A diffuse intrinsic pontine glioma, known as DIPG, is perhaps the most feared pediatric brain tumor because of the dismal survival statistics and devastating clinical course. This tumor tends to strike four to ten year olds with approximately half of these young children dying in the first year and 80-90% by the end of the second.

Despite more than 200 trials, no treatment has been found to be effective for long term survival in DIPG. For some children, steroids and radiation allow for a ‘honeymoon’ with relief of symptoms. But this is often temporary. With failure, even to the point of new motor problems, there was no published reports on cell lines, no animal models and no molecular/genetic studies.

The changes in the medical community’s approach to a disease are often evident much before the patient community is aware of them because the time from concept to study to publication of a research paper can take years. In 2008, change was beginning in DIPG research. The heart-wrenching post from grandmother “Sheila” launched an effort towards earlier awareness of research endeavors as well as international advocacy collaboration.

In 2005 the biopsy debate had heated up again. St Jude Children’s Research Hospital in Memphis, Tennessee (USA) responded with a concerted effort to approach families for post-mortem tumor donation for research resulting in more molecular information on DIPG. Since many

The IBTA has drafted a discussion paper, in conjunction with the Astro Fund, dealing with the difficult subject of post mortem donation of brain tissue for research. It can be downloaded from: www.theibta.org/IBTAWholeTissueBankingPaper.pdf and www.theibta.org/IBTATissueBankingPaper.doc If you have difficulty using those links, please email chair@theibta.org to be sent a copy by email.

dr.loice.swisher@utoronto.ca

In 1993, the standard of care for DIPG in the United States changed, as biopsy provided no improvement in survival over neuro-imaging in typical pediatric diffuse pontine tumors. Since that time, biopsies of pediatric DIPG have been uncommon resulting in the scarcity of tumor material for research. At the time “Sheila” wrote, there were no published reports on cell lines, no animal models and no molecular/genetic studies.

A family responded to the financial issues raised by these challenges by establishing a foundation called Tyler’s Treehouse (established in 2006), specifically started to fund the logistical aspects of this study. Over the ensuing years, many families with DIPG children have provided the ultimate gift to the research community involved with these studies of their child’s tumor tissue. Some families as far away as Australia and South America have donated their child’s tissue. The St. Jude efforts haven’t led to publication yet, however, The Hospital for Sick Children (‘Sick Kids”) in Toronto, Canada published the first whole genome analysis of DIPG tumors in February 2010.

Their French colleagues took a different approach, with a clinical trial including upfront stereotactic biopsy of pediatric DIPG. In the July 2007 issue of the Journal of Neurosurgery the surgical results were published. With 24 children there was no mortality and only two children had transient morbidity.

The combined effect of the French stereotactic biopsy results and the molecular analysis studies from “Sick Kids” in Toronto has led to renewed efforts for future clinical trials to include molecular analysis from stereotactic biopsy samples.

The development of animal models is also emerging. At the 2008 ISPNO (International Symposium on Pediatric Neuro-Oncology) conference in Chicago (USA), Dr. Oren Becher won the best basic science presentation award for his genetically engineered mouse model of brainstem glioma. The excitement of potentially being able to study this tumor in a mouse model has resulted in requests for Dr Becher’s mice from several others interested in studying brainstem glioma.

For some time, the non-availability of resected tumor tissue for the development of cell lines has met with failure, even to the point of new researchers being discouraged from pursing this direction.

In the summer of 2009, Stanford University in California revealed that Dr. Michelle Monje had been able to culture neurospheres from post-mortem pediatric DIPG tissue using a stem cell technique. This breakthrough in DIPG research at Stanford has lead to an EGFRviii vaccine being introduced to the pediatric brain tumor community for the first time as well as other research. Some of this has been funded through the Kyle O’Connell Foundation.

Truly exciting events have been two international meetings of researchers and clinicians to discuss DIPG. The Fondo Alicia Pueyo hosted the first symposium in Barcelona, Spain in February 2009. The second event was hosted by The Hospital for Sick Children in Toronto with funding support by Just One More Day and B.R.A.I.N child.

We are now seeing a change in DIPG research - and the international collaboration of parents, advocates, clinicians and researchers that is making this happen.

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http://www.artc.asso.fr

Soutenir la recherche en Neuro-oncologie
To support neuro-oncological research

Son objectif est de proposer des solutions innovantes, cliniques et thérapeutiques dans le domaine des tumeurs cérébrales.

The Association’s main goal is to improve fundamental, clinical and therapeutic knowledge in the field of brain tumour and to support hospital research.

Agir spécifiquement. To act specifically.

L’ARTC s’attache aux traitements de deux types de cancers : les tumeurs du cerveau et les complications neurologiques des cancers. The ARTC specializes in two pathologies: brain tumors and neurological complications. Two research laboratories are devoted to these tumors and are linked to other research institutes over the world. Moreover, ARTC recently decided to support neuro-oncology training and care in French speaking Western Africa.

Patients may contact ARTC for support and advice. Association pour l’Entraide et la Recherche des Tumeurs Cérébrales, Centre Hospitalier Pitié Salpêtrière, Fédération de Neurologie – Musée, 47, Boulevard de l’Hôpital, Paris 15.

By Dr Loice Swisher whose daughter Tori is a ten year medulloblastoma survivor. Loice is an FDA Patient Representative and emergency medicine physician. She is pictured here on a family vacation in Utah.

Tyler's Treehouse (established in 2006), specifically started to fund the logistical aspects of this study.

Oren Becher won the best basic science presentation award for his genetically engineered mouse model of brainstem glioma. The excitement of potentially being able to study this tumor in a mouse model has resulted in requests for Dr Becher’s mice from several others interested in studying brainstem glioma.

For some time, the non-availability of resected tumor tissue for the development of cell lines has met with failure, even to the point of new researchers being discouraged from pursing this direction.

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Lithuania is located on the eastern shore of the Baltic Sea. The country has been a member of the EU since 2004. The population of the country is over three million. The capital city is Vilnius.

The three largest neurosurgery centers in Lithuania are located in: Vilnius, Kaunas (second largest city) and Klaipeda (Baltic Sea port). The centers are equipped with sufficient treatment facilities and, significantly, highly competent doctors and supportive staff.

The largest neurosurgery center is in Kaunas. Every year it carries out approximately 70% of brain tumour surgeries in Lithuania. That is about 700 surgeries per year.

In Lithuania, brain tumours are diagnosed by CT or MRI. The principal mode of treatment is surgery followed by radiological treatment and/or chemotherapy.

The psychological aspect is very strongly expressed in a poem written by one Lithuanian brain tumour patient:

“Do not believe that everything in life is lost. If you yet are privileged with eyes and hands, though are buried deeply by the mounting costs, stand poised and make new lofty plans. Happiness does not require a lot, merely vivacity and courage, but lost- is not the one who comes back Not. But one that runs, himself abandoning all costs.”

There is also an urgent demand for accessible information about the disease, its symptoms, diagnostics, treatment methods, aftercare, living with/after the disease, nutrition, etc.
HELP AND HOPE FOR LOW GRADE ASTROCYTOMA PATIENTS

By Katie Sheen
Founder, Astro Fund

I am the founder of Astro Fund, a United Kingdom charity established in April 2001 which focuses on low-grade glioma LGGs.

Our main focus is fundraising to support LGG research, though we also offer information on our website and support through our international patient support group “Low Grade Glioma Support”, which I moderate with Julie Read.

We also work hard to raise awareness of the challenges faced by those living with this tumour type, in order to change things for the better. I am also a Patient Representative on the British Neuro-Oncology Society (BNOS) Advisory Group for the development of National Guidelines for four rare adult brain and CNS tumours.

I became involved in the brain tumour community when, in November 2000, my sister’s husband Paul had a grand mal seizure while driving to work one morning. Despite being in the outside lane and hitting the central reservation, a friend whom he knew well managed to stop his car and saved both their lives. To cope with the pressures that develop in this work, I remember that I am only a very small part of a much bigger picture. I develop in this work I trust in God.

To really guide them through every step of their brain tumour journey and information, we began our search for a cure. After a couple of months we found Dr. Jeremy Rees at the National Hospital for Neurology & Neurosurgery in London, who was trying to get funding for an LGG research project. At that time we could find no other LGG research underway in the UK, so we were devastated when his funding application was refused. My sister phoned me in tears to say that their “one glimmer of hope was gone”, so I simply said that we would raise the money ourselves. When I hung up the phone I wondered how I could make that happen! However by April 2001 Astro Fund was up and running, and the research project started within months.

To cope with the pressures that develop in this work, I remember that I am only a very small part of a much bigger picture. I trust in God. On a personal level, what gives me most satisfaction from my work is hearing our researchers telling me that they are able to give that opportunity to make a difference. On a charity level, the satisfaction comes from having funded five LGG research projects since 2001.

The biggest challenge of my work has been in becoming an independent charity. However I was well supported by many key people within the brain tumour community, and am extremely grateful for their help and encouragement.

What would be on my wish list? A cure has to be at the top of the list. Failing that, second would be a way of controlling low-grade tumours to keep them stable. How amazing it would be if they could be controlled by drugs in the same way that diabetes is managed, for example. Third would be that every family had a key worker, such as a specialist Neuro Oncology nurse, who had the time and resources to really guide them through every step of their brain tumour journey.

How do I relax outside of work? My main form of relaxation is spending time with friends and family. I have also practised yoga for about 10 years now, though still feel like a beginner! •

PROMOTING VITAL RESEARCH IN ITALY

By Francesca Scropetta
IL FONDO DI GIO

I am the Director of “Il Fondo di Gio per la ricerca sui tumori cerebrali ONLUS”, an Italian association set up to promote research into brain tumours, in particular childhood brain tumours. I have been doing this work since October 10th, 2002, the day my son died.

Hope and determination led me and my husband to become involved in this way. To cope with the pressures that develop in this work I trust in God.

When I see the same sweet smile of my brave son on the face of other brave children and adults coping with brain cancer, in the name of hope, then I feel satisfaction from my work. When I hear our researchers telling me that “Il Fondo di Gio” has improved and strengthened their way of going on with research, then I feel my son and all others live on.

The biggest challenge of my work in the brain tumour community is to win “the war”. Brain tumours are the first cause of cancer death in children. I can’t accept it - brain cancer is my enemy.

Our aim is to win the war against this devastating disease for the sake of all adults and children, who have to face very tough battles every day. Our weapon is the work of researchers in Italy which is financially supported by the donations that Il Fondo di Gio ONLUS receives. What is the added value of our weapon? It’s the hope for victory which bears witness to the braveness, the boldness, the pride of those who lost that war, despite winning all the battles.

Therefore, the first three things on my wish list would be: (1) to find well-trained doctors who are capable of diagnosing, treating and following patients during their journey, (2) to have a good rehabilitation during the patient’s journey and (3) to have a good palliation team at the end of life.

For relaxation outside of work I do gardening with my husband; also I follow him and my daughters playing golf. •

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Antisense Pharma is committed to the discovery and development of innovative targeted therapies for the treatment of cancer.

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Fluorescence-Guided Resections of Malignant Gliomas using 5-ALA

What kind of study is still necessary for determining usefulness?

By Walter Stummer, M.D.
Professor of Neurosurgery, Department of Neurosurgery, University of Münster, Germany

making the researchers believe that the technique could be useful in the final stages of tumor resection. The intra-operative MRI is not only available in highly specialized centers. Thus, a method which simply takes time and is in general expensive, suffers from brain-shift once the skull is opened and parts of the tumor tissue by red fluorescence.

Figure 2: Same view under violet-blue illumination with immediate demonstration of pathological marginal malignant glioma tissue by red fluorescence.

Figure 2

Figure 1

If you have been affected by a brain tumour, you are at the heart of everything we do.

In the UK, around 13,000 people are diagnosed with a primary brain tumour. Another 30,000 people will develop secondary brain tumours. Every diagnosis impacts on many other people. We can't talk to each anyone or you.

At present there is more and more evidence for a benefit of cytoreductive surgery in malignant gliomas despite the lack of randomized studies. In fact, it can be expected that more extensive resections set the stage for adjuvant therapies, such as concomitant radiochemotherapy, to be as effective as possible. It would be a pity if in other countries ALA were put through the same long-term process of approval as in Europe, via a prospectively-randomized study with progression-free survival or survival as endpoints, thus withholding this surgical method from many patients for years to come. Rather, ALA should be tested for what it is, a simple but useful intra-operative diagnostic agent, and any further studies should center on toxicological safety and specificity for showing tumor. It will always be up to the surgeon, his skills and his anatomical knowledge together with a careful utilization of neurophysiological monitoring techniques to achieve the greatest degree of safe resection possible.

Figure 1: Tissue at the margins of a resection cavity under white light. Differences in tissue appearance are difficult to distinguish.

[Editors' Note: Neither Professor Stummer, nor the IBTA, have any financial links with the makers of Gliolan, which is mentioned in this article. During the development of 5-ALA and the phase III trial Professor Stummer received consultant fees from Medac, the company marketing Gliolan in Europe. He is, however, neither a beneficiary of sales nor does he hold shares in the company.]
Living in the “NOW” and not the “WHAT IF”

By Joannie McCutcheon

Brain tumour survivor (United Kingdom)

I have two types of brain tumour, namely a meningioma in the left occipital lobe and a highly infiltrative oligodendroglioma in the right temporal lobe. They were diagnosed in February 2005 after I presented with a tonic clonic seizure. They are both WHO grade II.

I was told that the meningioma has possibly been in my head almost since birth. The oligodendroglioma has been there for “some time”.

I’m on a “watch and wait” policy having an MRI every year. I have epilepsy because of the tumours and take anti-epilepsy drugs. I had a sub-total resection operation (around 80%) of the oligodendroglioma in May 2007 that was highly successful.

I’ve just celebrated my five year “tumourversary” in February just past. It felt good.

The tumour has changed my life completely. To be told that you have not one, but two ‘lesions’ in the brain was absolutely shocking. I wasn’t even sure what a lesion was at the time.

I wasn’t able to do the work that I did prior to the tonic clonic seizure so eventually I was medically retired. The pressure and the stress to perform within the job proved too much for me. I had to travel with my job but because of my condition, insurance was very expensive to obtain.

Some peoples’ attitudes and assumptions can be strange when you tell them you have brain tumours so I now don’t usually mention them until they get to know me first.

I have realised how lucky I was to have been given the chance of the operation that was previously deemed inoperable. The success of it was due to the skill of the team of surgeons in the Vu University Hospital, Amsterdam and of the intra-operative equipment they utilised. They removed tumour 7cm deep I am so grateful to them.

I was medically retired. The pressure and the stress to perform within the job proved too much for me. I had to travel with my job but because of my condition, insurance was very expensive to obtain.

Although I now live in the UK my neurosurgeon asked if I could update him now and then. The last reply from them at New Year was that they were pleased to know that I was living a normal and fulfilled life.

Having the BTs has made me look at how precious life is.

I’m not in the paid workforce although I work on a voluntary basis in the Edinburgh Centre for Neuro Oncology (ECNO) in the area of IT consultancy.

I was invited to become the ECNO patient representative, and I’m involved with a variety of projects including reviewing documents such as Patient Information leaflets and participating in various events which ensures that the patient perspective is represented.

I was asked to build the Scottish Adult Neuro-Oncology Network (SANON) website and I continue to support this by being the webmaster. This keeps me busy, but I know that the time and effort that I invest in supporting the team is much appreciated.

I have established contacts with people with a similar diagnosis. We have a brain tumour support group in Edinburgh. There have been quite a few new patients there recently. It is good that they found us but sad that there are so many.

My first brain tumour friend, Manda, passed in February last year. We met doing Tai Chi in Maggie’s and stayed firm friends. Her partner and I are still in touch.

Do I have any tips for brain tumour patients? Here is a quote from a brain tumour forum in the US: “Unity is Strength, Knowledge is Power, and Attitude is Everything”. Also (3) try to attend a support meeting in your area. It’s good to know that you are not alone; (2) personally, I threw myself into research and felt that I was more in control the more I knew; (3) find all the professional help that you can. It takes time to get used to having a brain tumour and (4) hope, hope, hope and yet hope some more.

The first three things on my wish list in relation to this disease are (1) to find a cure through more research; (2) to raise the profile of this “Cinderella” cancer and (3) to make the public more aware of brain tumours.

Regarding parts of my journey as a brain tumour patient which could have been improved or delivered better, perhaps a tighter collaboration of all the different specialities required of central nervous system disease could be better but I think there is improvement now with the introduction of MDT’s (multi-disciplinary teams).

To relax, I practise Tai Chi and meditation. It helps a lot.

I try to live in the “NOW” rather than in the future “What if” scenario.

I find writing poetry about this journey very comforting. My “arty” creative abilities have re-surfaced and I love drawing portraits once more. I also dabble in the use of essential oils.

Brain like mine

By Joannie McCutcheon

Do you know what it’s like to have a brain like mine?

Well……………

it gives me a chance;

To do

all the things that I wouldn’t normally do,

To finish

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TO LOVE LIFE.
Four decades on from a malignant brain tumor diagnosis: George Plym’s amazing story

By George Plym
Retired automotive technician, Founder of WNCBTS (Western North Carolina Brain Tumor Support), and brain tumor survivor (43 years)

I was diagnosed in the early part of September 1967. It’s hard to remember that far back, but I do remember the first time I realized that something was wrong. I was playing Little League baseball as a third baseman in Spring Valley, Illinois. It was a routine pop fly that was hit to me. As the ball was coming down, I saw two baseballs coming at me and again I saw no ball. The next inning, a ground ball came to me and again I saw no ball. That was the first indication that I had a problem. I was never told directly from the doctors, but from what I understand, the doctors told my parents that I would probably live for maybe six months or a year. I showed them, didn’t I?

The brain tumor diagnosis has affected my life dramatically. But I think that it has infected my life in a positive way. It has made me realize how precious life is and I do not take it for granted.

I am medically disabled now, but I do remember the first time I received the information that I was told to get my affairs in order and I was diagnosed with a malignant brain tumor. The worst symptoms I have had to handle are probably seizures. I can handle visual impairment, headaches and loss of feeling in my arms and legs, but the seizures really scare me! I don’t like the feeling of not having control of my body and when you have a seizure you have no control at all. You just have to ride it out. I think the information that I received from my doctor could have been improved and delivered a lot better. When he diagnosed me with my number four recurrence, I was told to get my affairs in order because I wasn’t going to be around much longer. They gave me NO hope. Thank God I did not believe that for one second! I found a different doctor that had the same enthusiasm for life as I did. And we’re both alive! I always have believed 100% that I would survive my relapses. [Editors’ note: George has had eleven relapses.] I am a survivor and always will think that and I will continue to survive no matter what. There is no quitting in me. I’ll always think in my mind I am invincible! I have convinced myself that I will die from old age. I have told hundreds of people that I will not die from a brain tumor, I refuse to die from a brain tumor. That is the kind of mind set that I have.

Being the president and founder of Western North Carolina Brain Tumor Support (WNCBTS), I have a lot of contact with other brain tumor patients. I have contacts in 46 states in the United States, and eight or nine countries all over the world! What keeps me going other than my support group, friends and family? It’s my survival. Hope. Hope for a cure, and if not a cure right now, at least the hope that the tumor is slow in progressing. Hope is as important as medical treatment! Don’t take no for an answer, and fight to your last breath. So far, I seem to have been able to stay one step ahead of the tumor right now. New imaging and radiation have improved over the years. New chemotherapy agents have helped. New studies with vaccine therapies for brain tumors are promising. So knowing that, that’s what keeps me going. That and a strong belief in God. All things are possible with God. That’s what really keeps me going!

One of the three things on my wish list, would be to have all of the newest, promising treatments available to everybody! To relax, I enjoy playing the guitar. It started out as therapy. A doctor told me that I probably wouldn’t be able to play the guitar anymore. The multiple surgeries had left me with no feeling in my right hand and fingers. My right hand had curled into a ball. But I was determined to play guitar again and now I do! Not well by my standards, but I do play the guitar again. My hobby is repairing guitars and I really enjoy baseball. Especially the Chicago Cubs! I also really enjoy reading and replying to brain tumor survivors all over the world. Talking about playing the guitar, there is a singer named David M Bailey who is not only a singer and writer, but he is also a brain tumor survivor of 13 years. One of the songs that he wrote is called “Live Forever.” That is one of my favorite songs because that’s the way I feel. I’m going to live forever. Another song that David wrote is called “One More Day”. I listen to it nearly every morning when I wake up. It is powerful and very inspiring.

And one other thing... In my very early teens, I had a very noticeable gap in my teeth right in the front. My doctors told my parents that I shouldn’t be too concerned about having braces at this time because they felt that the chances were that I probably wouldn’t be around long enough to have the braces taken off. So we never did do that.

Three years ago it was my 40th anniversary of being a brain tumor survivor. I celebrated it by having braces to take care of that big gap in my teeth! And a year later, the braces were off.

Now if I die, I will die with a smile on my face! •

[Editors’ note: As well as being the Founder and President of Western North Carolina Brain Tumor Support in Asheville, North Carolina, George Plym is also on the Regional Advisory Board at Wake Forest University Baptist Comprehensive Cancer Center, where he has been treated.]