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Brain Tumour Patients

SPEAK OUT

You are not alone...

Brain Tumour

World Edition 2010

The Walk Around the World for Brain Tumours:

“We’re one step closer to a CURE!”

Produced by the International Brain Tumour Alliance: “Greater Knowledge, Greater Collaboration, Greater Hope.”
The International Brain Tumour Alliance (IBTA) is grateful for grants from the following companies:

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The IBTA welcomes undirected grants in support of its work. Please contact chair@theibta.org or kathy@theibta.org
Dear Reader,

Welcome to this magazine which 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, their family and caregiver, and so there are many articles that will satisfy the curiosity of brain tumour patients as to 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 sincerely and all those who gave freely of their time to respond to our requests for interviews and material.

Our best wishes and thoughts are with all those who might be travelling the brain tumour journey – a journey that no one ever seeks voluntarily to embark upon.

The Editors
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 (UK) 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 International Union Against Cancer (UICC) and later to the UK for a meeting of the then Cancer Voices organisation run by Macmillan. He also attended a brain tumour conference held in Wimbledon, South London on 21 September in conjunction with the Royal Marsden Hospital and the UK Brain Tumour Foundation (now no longer in existence). Kathy and Denis met and had several discussions and agreed that something needed to be done.

An opportunity arose in May 2005 when the World Federation of Neuro Oncology (WFNO) was scheduled to hold a conference 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 en route to Edinburgh via the USA, discussing the proposed new group with Rob Tufel in San Francisco, the then CEO of the National Brain Tumour Foundation and now with the Ben and Catherine Ivy Foundation.

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

At the same time Denis met Elizabeth Ritz and Carrie Sessine (Carrie is now in Washington DC) of Ritz Communications who advised Schering Plough in community relations areas.

At the Edinburgh WFNO conference

Douglas Gurerro, a neuroscience nurse from Royal Marsden, who was one of the facilitators at the Wimbledon brain tumour conference.

Rob Tufel, Sharon Lamb, Denis Strangman at the NBTF (now NBTS) offices in San Francisco, 2005.

Macmillan organiser Alex Gow

Zoe Hoppe

Cathy Cantone

Joy Schmidt

Carrie Sessine

Elizabeth Ritz

Cathy Cantone

Joy Schmidt

Carrie Sessine

Elizabeth Ritz

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At the Edinburgh WFNO conference
WFNO in Edinburgh and the IBTA was established on 10 May 2005 with Denis as Chair and Kathy as Secretary (now a Co-Director). Many of those fifty people are still active in the brain tumour community today but sadly several have passed on.

The early days
The support of Schering Plough in the early stages was key to the establishment because the IBTA did not wish to be a competitor for any of the existing national support groups by appealing for funding from among their supporters. Therefore a separate source of funding was necessary. Two other companies - Neopharm and Lilly - were also helpful at this time, particularly Dr Jeffrey W Sherman from Neopharm (now President of the Drug Information Association, DIA) and Uma Staehler from Lilly, who was later succeeded as a patient organisation contact by Susan M. Fox.

Another person who played a key role in those early days of the IBTA was Hubert Stuerzl from Schering Plough 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 trainee to travel overseas and obtain experience. Hubert was succeeded by Susan A Murphy.

In the first months of the IBTA’s existence, Elizabeth Ritz came up with the suggestion of conducting a global competition for a logo for the new group. An international panel of ten judges consisting of leading clinicians, patients and family members from within the international brain tumour community was selected by Kathy and Denis and thirty-two logo competition entries were ultimately received from around the world. Several of those entries had been prompted by Professor Tony Di Spigna of the New York Institute of Technology 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.

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 everyone’s horror) 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.

None of the funds accumulated from the Walk Around the World for Brain Tumours comes to the IBTA.

These two events - the Walk and the Week - have now become a regular annual fixture in the brain tumour community and by 2009 the number of supporting organisations around the world had grown to 182.

Another project which the IBTA initiated in the early years was to commission research by the Central Brain Tumour Registry of the United States (CBTRUS), headed by Carol Kruchko of Chicago (see interview later in the magazine), to estimate the annual worldwide incidence of primary malignant brain tumours.
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 (ECCO)/European Society for Medical Oncology (ESMO), British Neuro Oncology Society (BNOS), and Society for Neuro Oncology (SNO) conferences. Additionally, the IBTA has exhibited at the UICC World Cancer Conference and national brain tumour organisations’ conferences.

Denis (IBTA Chair) and Kathy (IBTA Co-Director) 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 of 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 (ECCO 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 52 (a UK based umbrella group of charities and not-for-profits focussing 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 and support groups in those countries where they do not exist and has recently given advice and encouragement to the Lithuanian group Kartu Lengviau (see later in the magazine) as it sought to assist patients and their families.

Denis and Kathy are assisted in their work by importer Chris Tse from New Zealand, who looks after the webpage listings for scientific and patient conferences, and by Sally Payne from Sydney, who is a lecturer in programming and maintains the IBTA database. Both Chris and Sally also give advice on policy matters.

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

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).
Tara Gent from Melbourne looks after other IBTA databases, particularly the record of the distances covered in the Walk Around the World events.

Retired accountant Fraser Legge from Surrey (UK) helps to keep the IBTA accounts in an appropriate format so as to fulfill our obligations as a company registered in the UK. Lawyer Jeanne Pasmantier from New Jersey, who is also an accomplished linguist, gives editorial and research assistance.

During the five years of its existence the IBTA has built up a unique international database of more than 3,500 contacts from the brain tumour patient and caregiver community, the medical professions, scientists and researchers, and commercial enterprises.

An electronic E-News bulletin is distributed regularly to these contacts and the IBTA has also involved them in on-line surveys to identify what their attitudes are on key questions. See later in this magazine for a summary of the results of a survey about revealing information about your brain tumour and its malignancy in public. We also conducted a survey seeking views on a theoretical proposal to deliberately delay neurosurgery for suspected glioblastoma so as to identify the efficacy of a novel chemotherapeutic agent.

There are also many other people from around the world who have given freely of their time and advice to generously assist the IBTA in research, writing, operational, translating, and other matters and to these we are very grateful.

The IBTA is also extremely grateful for funding support from a range of charitable trusts and individuals whose kind financial donations have helped the IBTA to continue its important work.
1) 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.

2) Professor Geoff Pilkington (Portsmouth, UK)
Professor Geoff Pilkington is 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.

3) Dr Rakesh Jalali (Brain Tumour Foundation of India)
Dr Jalali continues to organise 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.

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

5) Judy Gordon (Carer and Mother, Aberdeenshire, UK)

6) Kevin and Marguerite Sciku (patient, Virginia, USA)
Unfortunately 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.

7) Mike and Dianne Traynor (Pediatric Brain Tumor Foundation of the United States)
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.

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

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

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

11) Virginia Stark-Vance (Author of “100 Questions and Answers about Brain Tumors”)
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).

12) Verena Amberger-Murphy (Scientist, Dublin)
Now works as Translational Research Coordinator, All Ireland Cooperative Oncology Research Group (ICORG)/Molecular Therapeutics for Cancer Ireland (MTCI).

13) Zoe Hoppe (formerly Brain Tumour UK)
Zoe Hoppe retired from her position as Chief Executive Officer of Brain Tumour UK in September 2005.

14) 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.
15) Dr Jun Takahashi
(Kyoto, Japan)
Dr Takahashi re-established contact with
the IBTA at the WFNO meeting held at
Yokohama in 2009.

16) 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.

21) Katie Sheen
(SDRT Astro Fund, UK)
Katie runs the Astro Foundation, which
became a separate organisation from the
SDBTT in 2009. She and Kathy Oliver (IBTA)
recently teamed up to write a discussion
paper on brain tumour tissue donation.

22) Dr David Hamilton
(NZ)
David continues to practice at the
Wellington Hospital and is one of the few
brain tumour specialists in New Zealand.

2005 - Then and Now

17) Angela and Neil Dickson
(Directors, Samantha Dickson Research
Trust, UK)
Neil and Angela continue their energetic
work. SDBTT is now known as the
“Samantha Dickson Brain Tumour Trust”.

18) Theresa Hood
(Nurse Specialist)
Ms Hood is a Macmillan Clinical Nurse
Specialist in Neuro-oncology, Queen
Elizabeth Hospital, Birmingham, UK

19) Mario Moro
(Italy)

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

24) 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 and is a Director of
the Ben and Catherine Ivy Foundation.

25) Mary Hogan, Joan Wynne and Mary
O’Loughlin
(Brain Tumour Support Group, Ireland)

26) Tim Downing
(Australia)
Tim has retired from active involvement in
the brain tumour movement but keeps an
interest in the progress of the IBTA.

27) Mrs Jean Campbell (UK), Dr
Allesandro Perin (Italy), Ms Kathleen
Shirley (UK)

28) Shanne McNamara
(Edinburgh)
Shanne is a nurse specialist in Neuro
Oncology at the Edinburgh Centre for Neuro
Oncology (ECNO – University of Edinburgh).
She was previously Chairperson of the
Association of Neuro-Oncology Nurses in
the UK (ANON) and is nurse representative
on the Executive Board of the European
Association of Neuro-Oncology (EANO).

29) Pam del Maestro
Pam is a specialist neuro oncology nurse
as well as a leading brain tumour advocate.
She was the first Canadian to serve as
Chair of the North American Brain Tumor
Coalition. Pam and her husband, Canadian
neurosurgeon Dr Rolando Del Maestro,
founded the Brain Tumour Foundation of
Canada in 1982.

30) Dr Bali Rooprai
Dr Bali Rooprai is a Reader in the Scientific
Basis of Complementary Medicine, School
of Health and Social Sciences, Middlesex
University, UK with special research
interests in complementary therapies in
neuro oncology and brain tumour biology

31) Ms Emma Townsley (UK)
Macmillan Neuro-oncology Clinical Nurse
Specialist

32) Ms Sarah Levy (UK)
Neuro-oncology clinical nurse specialist,
Royal Free Hospital, Hampstead.

33) Dr Nikolai Rainov (UK)
a neurosurgeon at the Walton Centre for
Neurology and Neurosurgery NHS Trust and
the University of Liverpool.

34) Ms Helen Lee (UK)
Royal Hallamshire Hospital, Sheffield
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 inbetween, patients, caregivers, medical professionals, researchers, scientists and others with an interest in this devastating disease put on their walking shoes to participate in this 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 around the world – a distance of 75,000 miles (or 120,000 kilometres). In 2009, the target was five times around the world or 125,000 miles (200,000 kilometres).

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In 2009, the target was five times around the world or 125,000 miles (200,000 kilometres).

All three years saw the target totals reached and then some! To date, the Walk Around the World for Brain Tumours has involved 109,488 people participating in 275 walks in an average of 20 countries each year. They raised the equivalent of at least US $14.6 million for local brain tumour charities and research organisations. No funding from any of these walks goes to the IBTA.

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.”

Some 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 walks that took place in the past which reflect the determination, inspiration, endurance and camaraderie that these activities engendered.

Each and every step taken on these walks is one step closer to a cure for brain tumours. And 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 20 countries walked in
- **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 were given to the IBTA.*

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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.
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. 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.

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 incredible - 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.

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.
Kick Biker With A Mission

KLASKE HOFSTEE
Stichting STOPhersentumoren.nl

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 Faaij 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 keep 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 peddles. 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.

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. ✷
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. 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 many children we made a decision to take the Ride for Kids® program across the US, leave our careers behind, and formed the Pediatric Brain Tumor Foundation to begin a national effort of support for research and patient families.

I have filled many roles for the PBTF but the role that relates to the brain tumor movement has been that of directing the pediatric brain tumor programs of the PBTF.

I am also a patient advocate advisor to U. S. agencies like our National Cancer Institute; the National Institute for Neurological Diseases and Stroke and most recently for the U.S. Department of Defense Research funding program. I have also served on grant review committees for the NCI and participated in the American Association of Cancer Research's Scientist to Survivor Program. I have been a founding member and served on the board of the North American Brain Tumor Coalition and the Alliance for Childhood Cancer and I have served as a member of the Patient Advocate Research Team (PART) programs as the representative for brain tumors to the NCI’s brain tumor SPORES (Specialized Programs of Research Excellence).

In addition to the research efforts I took on the task of creating written resources for families of patients and survivors. These pamphlets are written in English and Spanish and distributed world wide to families, medical institutions, and medical and social work professionals. Additionally the PBTF created a webcast that brought medical and social work professionals to patient families via web broadcasts that were archived on our PBTF website and also distributed on CDs as educational tools on topics relevant to families of children with brain tumors.

When we began our national effort with the PBTF and the Ride for Kids® the work became our lives. We knew we could not do this alone so we sought out the support of members of the motorcycling community and members of the corporate world, the American Honda Motor Company. We introduced them to this disease and solicited their help to fight against it.

I have watched the field of pediatric brain tumor research grow nationally and internationally and know that the PBTF’s contribution has been a big part of that growth. We also supplied the grant funds to create and support the Central Brain Tumor Registry of the United States (CBTRUS) which started in 1992. My husband served as one of the founding board members of the CBTRUS and I now serve on their board. The existence of the CBTRUS has allowed us to determine the statistical scope of this disease and its impact in the North America.

The PBTF supplied a founding grant to the Society of Neuro Oncology which established its international medical journal, “Neuro Oncology”.

The PBTF has funded more than 50 research institutions nationally and internationally and has established three Pediatric Brain Tumor Foundation Research Institutes in the United States and Canada.

We have funded numerous collaborative research conferences nationally and internationally.

We have supported 638 young survivors through our scholarship program which first began in 1984.

When we believed in the need
for new programs we have been determined to not dwell on our challenges but to find a way to move around them and work even harder to achieve our goals. Mike had a slogan that he kept on his desk and I am reminded of it when things become a challenge today, it reads, “I don’t care about the storms you encountered, did you bring the ship in?”

The first three items on my wish list for brain tumour patients would be: (1) treatments that would cure their disease; (2) programs that would allow survivors to lead active, independent and productive lives: (3) determining through research the genetic causes that drive these diseases and finding a way to reverse those through novel, less invasive treatments.

To relax, Mike and I would take the opportunity as often as we could to travel on our motorcycle across the US and to other countries.

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**A step closer…from four to 85, all ages walk for brain tumours in the Netherlands**

Klaske Faaij-Hofstee, Chairman of Stichting STOPhersentumoren.nl (The Netherlands) let us know that: “Saturday November the 7th (2009) we had a great Walk4Brains. In the Netherlands 600 people walked for hope in four different places and together we walked 4,863 kilometers and gathered over 25,000 Euro for research. The Walk4Brains in Driebergen was opened by the Mayor, and he said: ‘It is so important what STOPhersentumoren.nl Foundation does, because it seems like more and more people around us have a brain tumor. And when you finally experience what their fate is, you want that much money is raised for brain cancer. I…call on everyone to support them.’ Our eldest pedestrian was 85 years old and our youngest four years old. Next year we will walk for brain tumours again!”

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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, she and I had no clue as to what a brain tumour was. I was shocked at the lack of readily available information about brain tumours and that led me to search the Internet and to make contact with other carers and patients.

I started locating useful information such as the Primer booklet published by the American Brain Tumor Association (see http://www.abta.org/index.cfm?contentid=170&Primer-Basictumorinformation) 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 Marg’s Journey, before they were uploaded. The diary is still there and can be accessed at: www.

My wife developed an attitude of ‘realistic hope’ as her guiding star...

Marg Strangman

ozbraintumour.org/Journey.htm. I stopped counting the number of visitors after the total reached 100,000. Some of these contacts might have been thousands of miles away but we all engaged in sharing and support.

Not everyone will seek to establish such contacts and I can appreciate that attitude.

Families deal with these challenges differently. Friends and previously close contacts might retreat out of fear and confusion. Others may become closer and new friends might emerge. Some will want to offer help. Don’t reject those offers - accept what is useful so that 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?
The Association IRENE Onlus was created in 2005 by brain tumor patients and their families with the aim of promoting a better knowledge and quality of care for patients and caregivers.

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

IRENE’s fund raising 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 to 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 Pamphilii.

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 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 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’accesso ai diversi trattamenti e ai diritti del malato.

L’attività di IRENE Onlus si basa sul contributo diretto dei 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 (borse 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 Pamphilii di Roma.
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 fulfilment 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.

The biggest challenge of my work in the brain tumour 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 tumour 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!
My brain tumor was diagnosed after my first surgery as "oligoastrocytoma"; 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 diagnosis. I feel it doesn't matter as much to me if someone is upset by something I said if I believe it.

I am a physician. I specialized in Family Medicine for six years and now I work for an "Urgent Care" system. The Urgent Care centers are medical offices where patients are seen for illness and injury when they are unable to get an appointment with their regular doctor.

My family and friends have shown me great support since my diagnosis. I was training to run a half marathon when I was diagnosed, but I was unable to run the race that year as I was recovering from two surgeries to remove as much of the brain tumor as possible.

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 brain cancer 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 both 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. Working as a physician is a stressful job that is complicated by the possibility of lawsuits in the United States. I find it more stressful to be a physician with brain cancer; I fear unhappy patients may use that against me in a lawsuit.

Editors' note: For more information on the "ROC on!" team see www.roconnow.com. There is also a ROC on! contact on Facebook.
I am Founder and Chief Executive of Hammer Out Brain Tumours; Founder Member and Trustee of Brain Tumour Research and a patient representative. I have been doing this work since my husband was diagnosed with a malignant brain tumour in July 2001.

When we first heard Paul’s diagnosis, we turned locally to support groups or a network of support. We very quickly realised that there was a gap in the South West of England for this service for brain tumour families. I was determined that I wanted to change this so it would be different in the future for other families facing this disease.

I am learning over the years that the way in which I cope with the pressures of this work is to be honest with my family and the team I have around me at work. This is something I encourage with all the Hammer Out team. If I find that the pressure gets too much and if my diary allows it, I generally try to take a couple of days’ leave to give myself time out of the environment. It is very difficult working in a charity where a lot of the pressure is what I put on myself to succeed in achieving the best possible outcome for brain tumour families. I have such a passion to make a difference in the brain tumour community that at times it can be an obsession. I am trying to achieve a healthy balance between my passion for my work and my family life.

Knowing that the work we do at Hammer Out is helping brain tumour families gives me the most satisfaction from my work. In terms of support, every time we help one family we feel as if we have conquered the world and we have made a difference in the lives of people affected by this dreadful disease. In terms of putting money into research, the local projects we are currently involved in makes the link we have with local hospitals and universities stronger.

Everything that I have done in the brain tumour community since Paul’s diagnosis and subsequent death has been with the support of my family, friends and local church. As a committed Christian, all the work I do is to honour God. The ethos of the charity is to act honourably at all times in all that we do to promote the cause. This applies in particular to the challenges we have faced in developing this work.

The biggest challenge has been to raise public awareness, locally and nationally, of the effects of living with a brain tumour. This has incorporated the need to work in harmony with other charities and to network effectively to the advantage of the brain tumour patient and family, and also to communicate effectively with the press with integrity and with an approach that commands respect.

The first three items on my wish list for brain tumour patients would be: (1) a cure for all types of brain tumours, benign and malignant; (2) better support for brain tumour families – for example, a brain tumour unit where you go for your clinic appointments and then you have respite care and (3) increased public awareness of the overall effects of brain tumours.

I relax by chilling out with my family in front of a good chick flick! I get my children to choose a film which they know I will like and then we all sit down and watch it together. My other passion in life is football and although I don’t relax when I’m watching it, I love nothing than standing in the terraces shouting for my team, West Ham: “Come on you Hammers”!

Penny Bowman, New Zealand, worked closely with the IBTA during 2005-2006 when she and her late husband Dan fought a strong campaign to convince the New Zealand regulatory authority to fund temozolomide. They were ultimately successful.

Dr Francesc Graus (left), of the Servei de Neurologia Hospital Clinic, Villarroel, Barcelona, with the IBTA Co-Directors at the EANO meeting, Vienna, 2006.
Africa: Dying in Pain a Reality for Most Africans

By Anso Thom, Health Writer,
Health-e South Africa (http://www.health-e.org.za)

Introduction: As far as the IBTA is aware the facts in this 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.

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 the morphine area is the development of a sub-cutaneous, slow-release, hydromorphone polymer implant by well know neuro-oncologist Dr Stuart A Grossman (USA) and colleagues. Its widespread adoption could overcome many of the problems relating to illegal activities in morphine distribution.

Editors

Here we were in the main military hospital in Malawi and they had no morphine...

"Dar Es Salaam — People living with cancer are dying on the African continent in terrible pain as they present too late with advanced cancers that are mostly incurable by the time they reach a health worker and if they do reach help most of them find that effective pain medication is not available.

Lucy Finch, a stately Malawian nurse who worked in Uganda most of her life, shared with delegates at AORTIC’s 7th International Cancer Conference her reason for becoming a palliative care worker which led to the establishment of the Ndi Moyo palliative care centre, 100 km east of Lilongwe.

"In 1998 my younger sister had AIDS and was dying of cryptococcal meningitis and I came home to Malawi from Uganda to nurse her at the military hospital. There was a soldier in the next room who was dying in pain. The young man screamed and cried for three days and when I pleaded for pain medication I was told that they only had paracetamol.

"Here we were in the main military hospital in Malawi and they had no morphine," said an exasperated Finch.

There and then Finch made a promise to herself that she would dedicate the rest of her life to promoting palliative care and "prevent others from suffering the same fate as the soldier". Malawi currently has 18 palliative care centres, but not a single oncologist, no cancer centre which means no radio- or chemotherapy treatment for adults.

Uganda’s first palliative care nurse Rose Kiwanuka revealed that her country had one cancer unit for 32-million people. This unit also sees patients from Rwanda and the DRC.

"How many people can afford to reach treatment? This is why many..."
Kiwanuka said despite the service being available they constantly struggle with power outages which could last anything from a day to a week.

Jim Cleary told delegates that 80% of the world's morphine was consumed by 10 countries in the world with the United States dispensing an average of 60mg of morphine per person per year compared to Africa with 0,0002mg per person per year.

Low and middle income countries - which host 80% of the world's population, more than half of the world's cancer patients, and more than 95% of people living with HIV - account for just six percent of morphine consumption.

Credited with promoting palliative care and access to morphine in many Africa countries, Dr Anne Merriman said "no African should suffer severe pain".

She said there was a huge need in the francophone countries, adding that 57% of Ugandans and a staggering 85% of Ethiopians never saw a healthcare worker in their lives.

A country assessment presented by Merriman showed that 10 000 people in Sierra Leone were currently in desperate need of palliative care.

She said there was a "big problem" in Cameroon where there is only one site providing morphine. "People are very poor and have to pay for their healthcare," she said. Almost 100 000 people are in need of palliative care in this country.

Morphine arrived in Ethiopia this year where 180 000 people are thought to be in need of palliative care. "The suffering in terrible and many people are members of the orthodox church which believes you have to suffer if you wish to get to heaven," says Merriman.

In Malawi, an AIDS-related cancer - Kaposi Sarcoma is common with 165 000 people currently in need of palliative care.

Merriman shared the story of a 24-year-old dying man who had to travel to hospital every day on the back of his 13-year-old 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.

Dr Liz Gwyther presented statistics which showed that while the global mean in terms of morphine access was 5.9 - the African average was 0.45.

"We know more, but fewer people are getting pain control," she said.

Gwyther said 70% of the more than 10-million cancer patients diagnosed annually suffered pain. Between 60 and 100% of the more than 33-million people living with HIV experienced pain.

African countries that had introduced palliative care with access to morphine possible include Zimbabwe, South African, 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 healthcare systems, greatly exaggerated fear of addiction, severe "morphinephobia", inadequate knowledge about morphine and overly restrictive laws governing the use of narcotics. •

Reprinted from the AORTIC Newsletter, March 2010, Issue 16, with kind permission of AORTIC (African Organisation for Research and Training in Cancer – www.africa.aortic.org), and with kind permission of Anso Thom (Health Writer) and Health-e South Africa.

Liliana de Lima, Executive Director, International Association for Hospice and Palliative Care (IAHPC), in front of IBTA poster at UICC Congress, Geneva.

The IBTA Chair (left) with patients and caregivers at a meeting at Royal Melbourne Hospital, Australia. Second from the right is neurosurgeon Dr Kate Drummond who is Chair of the Victorian Clinical Oncology Group Neuro-oncology committee.
I am the Chief Executive of Brain Tumour UK, an organization which provides personalized support online, on the phone, by email and via support groups. We also fund research and raise awareness about brain tumours. Among other things, we’ve just committed to raising £500,000 for our latest research lab, which opened in February 2010.

I have been leading 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.

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 2001 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.

Sue Farrington Smith
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 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 the BT patients/caregivers is to persuade them to fight and to hope. For the BT association the challenge has been: to convince people that work should be done in a "scientific" and "non-emotional" way.

The first three items on my wish list for brain tumour 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 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.

Outside of work I enjoy relaxing over a glass of wine, sunbathing and watching Disney DVD’s with my children.
Mo Mowlam Survey

Initial Overview for the IBTA
Prepared by JACKIE WEAVER

Over 350 people participated in a 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 was “benign” and “treatable”.

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 to 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. Mo died on 19 August 2005. A new television drama about her life reveals that her then physician (Dr Glaser) had told her she had a malignant brain tumour but she insisted on that fact being kept confidential. Dr Glaser has now spoken about these events in the television drama, after first discussing it with Mo’s widower, Jon Norton, who has subsequently died. Norton and her doctor were apparently the only two people who were aware of the true facts of her medical situation when she was a Government Minister. (See: http://www.guardian.co.uk/culture/2010/jan/17/real-mo-mowlam-channel-4 for further background information).

The brain tumour journey is full of difficult choices, for the patient, caregiver, family, and the health professionals who treat the person with a brain tumour. We are interested in obtaining an impression of what our readers believe on this question of disclosure and would be grateful if you could complete the following questionnaire. The results will be reported in a de-identifiable form in a future issue of the IBTA E-News.

**The questions:**

**Question 1:** In this instance it is important to know what each category of reader believes and so we ask you to identify the category which best fits your situation

**Question 1:** I am a patient (please indicate grade and type of brain tumour below)

**Question 2:** What would you do in this situation if you were a patient?

**Question 3:** What would you do in this situation if you were a doctor?

**Question 4:** Please indicate your residency

**Question 5:** Other comments

Who responded to the survey?

These preliminary findings are based on the first 337 responses to the survey. More than half of these respondents (192) were health professionals:

- Oncologists and neuro-oncologists (65 respondents)
- Neurosurgeons (42)
- Nurses (33)
- Allied health workers (30)

The remaining respondents were:

- Caregivers/ex-caregivers/family members of brain tumour patients (65)
- Brain tumour patients (36)
- Interested members of the public (41)

A high proportion of all 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 MM (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 those who would opt for disclosure did qualify this in some way – for example by saying they would tell...
only their superiors at work, and would ask for it to be kept confidential, and/or would emphasise to those they told that they were still competent to carry out their duties.

(It seems they may have a rather misplaced faith in human nature here – several patients referred to the lack of understanding about the nature and effect of their illness that they sometimes experienced, in the workplace and elsewhere.)

Of the other groups:

• Neurosurgeons were more likely than oncologists and neuro-oncologists to say they would do the same as Mo Mowlam, and not disclose their condition. There was a roughly 50:50 split between those who would do this, and those who would disclose the condition.

• Neurologists and radiation oncologists were much more inclined to disclose, than to not disclose, the facts of their condition.

• Nearly twice as many nurses said they would disclose as said they would not disclose, while the reverse was the case for allied health workers.

• On balance, those who defined themselves as interested members of the public tended to come down on the side of non-disclosure rather than disclosure.

What would they do if they were the doctor?

Again, there was a discrepancy between the views of patients/carers, and those of oncologists and neuro-oncologists. Around half of both patients and carers, but fewer than one in four of the oncologists and neuro-oncologists, were adamant that patient confidentiality, and respecting the patient’s wishes, should come before any other consideration.

This is not to say that there is not a very strong commitment to patient confidentiality among the latter group – the most common position (applicable 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 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.

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 case.

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.

• 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.

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 tumours, including:
  - 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
• Should a doctor continue to respect patient confidentiality after the patient's death?
• The relative merits of trying to continue to lead a normal life after a diagnosis such as this, versus giving up work and spending more time with one’s family and friends
• Who to confide in (employers, friends, family members), and how to go about this

Responses to these questions, and others, will be explored in more detail at a later stage, as will differences in responses between UK residents, and those living outside the UK. Subscribe to the IBTA E-News to keep up to date:

http://www.theibta.org/subscribe.html
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 chemo-radiotherapy in glioblastoma the regime became standard practice throughout the world almost overnight.

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.

For many years the value of surgery in high grade glioma had been in doubt.

We now believe that maximal safe surgery not only improves the condition of the patient but can extend survival when followed by appropriate post operative treatment. So convincing is the surgical evidence that new methods for enhancing removal such as intra-operative MRI or fluorescence directed surgery are being introduced as standard in some units.

Furthermore it took 30 years of experimenting with chemotherapy before Roger Stupp chose the right drug given in the right way and showed, without doubt, that survival could be improved. In both these examples persistence and vision was needed to produce the right results.

We have learned that ‘malignant glioma’ is not one disease but a spectrum of diseases whose behaviour varies not only according to the way the tissue looks under the microscope but also, and often more importantly, according to the molecular changes that can now be identified. After all, it is these abnormalities that determine the behaviour of the cells.

Oligodendroglomas with defects on chromosomes 1 and 19 behave better than those without these abnormalities. Glioblastomas that are prevented from expressing the MGMT gene seem to have a better outlook than those that can.

These properties are now used for determining just what treatment might be best for a patient and which clinical trials they may be eligible for. Other molecular determinants such as IDH-1 are being explored for a role in prediction of patient outcome and perhaps choice of treatment.

In the future it is likely that optimal management will be individualised to the molecular profile of a particular tumour.

As well as improving the survival prospects of patients with these diseases it is just as important to understand and address their support needs.

Damage from the tumour itself, and from the treatment, can lead to problems with cognition, communication, mobility and thereby to the social, employment and economic consequences that follow. As patients live longer so these issues demand more comprehensive and durable solutions.

The involvement of specialists from ancillary disciplines, at an early stage, can be vital to this type of care. Crucially, careful thought must also be given to limiting treatment related damage in the first place. For example we can employ increasingly sophisticated radiation techniques to spare normal tissue and limit the late radiation damage that might manifest, particularly since patients are living longer and they are receiving adjuvant treatments that may enhance normal tissue damage.

Undoubtedly we have made significant progress for patients with brain tumours but it is nowhere near enough. We must ask where the next steps in improvement will come.
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 recognise the diseased cells and eliminate them 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 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.

So, how optimistic am I?

Well I do not think a cure for malignant glioma is imminent but I do believe that even in the next few years the new approaches will be integrated with our increasingly sophisticated surgical, and chemo-radiotherapy schedules to deliver longer and longer survivals.

Treatments will be tailored to the particular tumour type based on its molecular profile in order to maximise the chance of benefit while avoiding unnecessary and useless toxicity.

Along with this we must continue to understand the physical and psychosocial consequences of having a glioma and organise appropriate support.

A magic bullet in this disease is unlikely. Progress will be hard won and will arise from a marriage between basic and clinical science. In all of this persistence will be key and in this we have history on our side.

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A step closer... Informacine Savaite in Lithuania

Ugnius Smalskys of Karču Lengviau (the Lithuanian brain tumour support group) explained that the Karču Lengviau community arranged activities in connection with the third IBTA International Brain Tumour Awareness Week (“Informacine savaitė” in the Lithuanian language) during the first week of November. These included a short walk with 15 people who achieved a total of 15 kms for the World Walk, a Holy Mass for patients and their families, a broadcast on Lithuanian national television and a Mini Conference in Vilnius Emergency University Hospital. A new Lithuanian book from Karču Lengviau for brain tumour patients was also launched in this week. It covers important topics such as treatments, psychological aspects, convalescence, etc. The book is distributed free to brain tumour patients in all of the Lithuanian neurosurgery centres.

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A step closer... IBTA applauds Hong Kong Braintrekkers

Hong Kong: Dr Danny Chan from Hong Kong advises that 250 “Braintrekkers” each walked 6 kms on 28 November to add 1,500 kms to the World Walk target. That is a great achievement!
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 donated 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 tumour) 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 tumour 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 Cruickshank 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 where many brain tumour cases go untreated due to lack of equipment, among many other challenges.

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 paediatric surgeries. While this is good news for others, it comes too late for young Jerrold Chazika who lost his battle with a brain tumour 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 tumour. 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 tumour. 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.

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.

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.

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 tumour 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).
distributed clothes to a needy brain tumor community in the Harare suburb of Sunningdale. The clothes were donated to us by a Rotary Club in Australian via the Rotary Club of Highlands (Harare). We have sourced adult diapers from the United Kingdom and distributed them to our members who are under palliative care.

The ZBTA has established parent forums that are run in Harare on a monthly basis. This is an opportunity for parents to meet with junior neuro doctors and ask questions about any of their concerns. The first two such meetings this year have been so successful that we decided to make this a permanent event as long as the neurosurgeons are still available to meet over the weekends.

We have also engaged the Ministry of Health to try and do something about the scarcity of neurosurgeons in Zimbabwe.

Lack of specialists and equipment
In Zimbabwe we only have 4 fully qualified, registered neurosurgeons for a population of 14 million. Helped by our determined advocacy work, two neurosurgeons have graduated from the medical school and this has given hope to a near-collapsing service. No neurosurgeon had graduated from the medical school for the last twenty-eight years despite the medical school having the capacity to produce such. There was simply no support. But thankfully and eventually, these two neurosurgeons were supported and finally made it!

We are so happy about this achievement because this brings new energy and expertise to our neurosurgery services and these two neurosurgeons are very forthcoming in a lot of ways.

The ZBTA has also sourced some much-needed drugs through a very special friend in America. Unfortunately she too died of a brain tumour. But before her passing, she also managed to find some medical equipment for us with a sum total weight of 2560kgs. This consignment had among it some bed monitors and an ultrasound scanner.

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.

But we are grateful that the world outside of Zimbabwe’s borders has helped us and that our own dedicated band of determined volunteers has made such a difference in the lives of brain tumor patients in our country.
Nothing can prepare you for the shattering experience of having a child diagnosed with a condition that cannot be remedied. This is the story of my son Jerrold. My name is Esteri Chekeche and I am 31 years old. Together, we walked his short journey to eternity as a result of a brain tumor. At the age of seven he succumbed to the condition and died.

Hope, love and gratitude replaced hopelessness, anguish and despair and this has given me the reason to share my life and my experiences.

From my first marriage I had two children - a boy aged seven, Jerrold, and a girl, Patience, aged 13. I remarried in 2008 and was expecting another baby when my son Jerrold complained of persistent headaches and vomiting in early April.

We took him to the local clinic where he was treated for tonsillitis. After a week of medication there was no change. Investigations were redone and they started him on malaria treatment for suspected jaundice. Later he tested negative to malaria and treatment was stopped. The next thing was that Jerrold could not walk properly. He could not use his right hand and one side of his mouth was drooling. He also complained of losing his sight. This was the beginning of pain and confusion, and became my daily battle which caught me unprepared.

I finally gave birth to a baby boy on April 22, 2008 and named him Adolph Jr. After being discharged from the maternity hospital I discovered that Jerrold’s condition was deteriorating. We took him to the hospital on the 21st of May 2008 and he was admitted immediately. After undergoing several medical procedures, blood tests and C.T scans the sad news came - he had a brain tumor. This was on the 29th of May 2008.

After the devastating news I met the Zimbabwe Brain Tumor Association (ZBTA) staff, the Director Mrs Mungoshi and Maxwell Chambari from KidzCan who assisted me with the payment of the C.T. scans and other expensive medical procedures. I was given a book called “Essential Guide to Brain Tumors” which proved to be very useful. The ZBTA and KidzCan paid hospital visits and provided us with counselling and goodies which gave me hope and the courage to soldier on.

The doctors could not ascertain the name of the tumor due to the fact that no biopsy was taken because of the location of the tumor. It was reported that the tumor was located in the midbrain and part of the pons extending into the supratentorial area and causing hydrocephalus.

The neurosurgeons said it was impossible to operate on. To relieve the pressure from the brain, a VP shunt was inserted on the 11th of June 2008. Jerrold’s condition changed for the better after the VP shunt’s insertion, however radiotherapy treatment was suggested as follow up support.

Jerrold was referred to the radiotherapy department through a letter from the neurosurgeons. Radiographers requested a biopsy while the neurosurgeons argued that there was no way they could take a biopsy given the dangerous location of the tumor.

The radiographers requested a letter from the senior neurosurgeon authorizing them to go ahead with radiotherapy without any biopsy taken, citing the fact that the initial letter was inadequate since it was signed by a junior neurosurgeon. I was promised that the way forward would be mapped. Nothing materialized and I was kept going around in circles. It was then reported that my child’s medical reports were missing.

Nursing a newly-born child and caring for an admitted sick child was painful and exhausting. As there was no treatment being given to Jerrold except for diclofenac (a pain killer) I decided to take him home for home-based care. His condition was deteriorating.

As a family we decided to talk to Jerrold about his condition. This was necessitated by the fact that he kept asking if he was dying. Prior to his condition we used to talk about life and death issues in a religious context therefore it was easy to refer to this subject of life and death.

The month of September was the worst when Jerrold’s condition deteriorated. He stopped communicating, became blind and all movement ceased.

We literally watched him die slowly and painfully. I saw part of me dying with him as I loved him so much. Home-based care became challenging because of Jerrold’s condition and we took him to the hospital where he died.

My experience gave me the determination to join ZBTA and raise the profile of awareness among the public and support patients and their caregivers on the brain tumor journey. The challenge ahead of me now, as a ZBTA team member, is to support brain tumor patients and highlight the early warning signs and symptoms of brain tumors to the public. It is my hope that through all this, a life will be saved and those who are sick might not have to go through the same challenges that my beloved son went through.

I realized that I gave my child all the support I could. I am grateful that I went through all this and today I have a life full of meaning because in my heart Jerrold lives.

Unlike my other marriage, fortunately this marriage survived despite what we went through. I am grateful I have learned to give love and support through my experiences.

Jerrold’s life brought the family together. May his soul and all brain tumor angels rest in peace.
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/

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

“The dramatic cover of the Stichting STOPhersentumoren.nl awareness raising book, “1500 Hoofdzaken”

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 tumor patients. Klaske has added some powerful quotes. Together they paint an impressive picture of what having a brain tumor really means.

“I hope that more and more support and understanding can be given to brain tumor patients,” said Klaske.

For more information on these two exciting projects, contact Klaske at khofstee@STOPhersentumoren.nl
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 hemianopy 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 - absolutely yes. I have been lucky to have 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).

LONG TERM SURVIVOR

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 hemianopy and staggering.

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Beating Brain Tumours: Students Stride for SSBTR

Students Supporting Brain Tumor Research (SSBTR) is passion. SSBTR is leadership. SSBTR is a cause, a drive, a mission. Here, Roxie Goldberg, one of the student Co-Chairs for this project, describes how motivation and inspiration are helping a determined group of American high school and college students to raise awareness of brain tumors.

Students Supporting Brain Tumor Research (SSBTR) was founded in 2002 after the devastating deaths from brain tumors of three Arizona (USA) high school students.

When research pointed out that other than leukemia, brain tumors are the number one cancer killer in teenagers, a decision was made to do something about it. Students Supporting Brain Tumor Research was the brainchild of teacher Steve Glassman. He saw the organization as one being run by students. His vision was that not only would SSBTR provide a means of helping to fight the number one killer of high school age young people, but the initiative would also give students involved with this project the opportunity to become community leaders and philanthropists.

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 raised was donated 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 they 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 mission 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.


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 Jesse gained was unlike any other.

Mikaela Gibson was the Public Relations Committee Chair. Mikaela’s responsibilities included writing press releases and contacting local and national newspapers, magazines, radio, and television stations. Taking on these tasks allowed Mikaela to get a taste for life as a public relations manager, and similar to Jesse’s experience, enabled her to develop skills as a leader.

The combined efforts of the university students’ logistical endeavors and the high schools students’ coordination of schools, entertainment and advertising, resulted in a day of incredible success.

Taking place on a beautiful, sunny, February afternoon, the 2010 9th Annual Students Supporting Brain Tumor Research Walk-A-Thon was held at the Arizona State University Memorial Union.

The busy day began for the student volunteers bright and early at seven o'clock am. Organizing 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 big day, 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 journey from May 2009 to February 2010 was an exciting learning experience for all. Jayden Miller, SSBTR 2010 Co-Chair, said: “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.”

Little did the original student volunteers know that just nine years later, the project they pioneered would raise over one million dollars.
Helping Swedish Patients Cope with a Brain Tumor Diagnosis

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

I’m 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 1995. 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 opinion when the tumor recurred. I came in 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. However, it is very hard to lose people I come to know in this work. I strive to even out the odds for the disease and for each year we can see more and better modalities even for the most severe diagnosis.

The thing that gives me the most satisfaction from my work is the possibility of spreading information regarding new modalities/therapies and that I help people get together to give each other support.

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 is horrible. The way they treat a person as a “diagnosis” rather than a human being is beyond understanding. This prevents them to catch up with promising developments in the field and it is a true challenge to get through to them.

My wish list for brain tumor 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 knows 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.

A step closer... students step out for brain tumours

On 7 March 2009, Students Supporting Brain Tumor Research (SSBTR) held their 8th Annual Walk-a-thon in Phoenix, Arizona and on 28 February 500 people took part in the inaugural SSBTR Tucson walk at the University of Arizona Mall. There were 3,500 walkers each walking 5 miles and $202,000 raised for brain tumour research and support. In 2009, SSBTR passed the $1,000,000 mark in total funds raised for brain tumour research!
FOCUSING ON FUND RAISING AND SUPPORT

PAUL CARBURY
Chief Executive Officer, Samantha Dickson Brain Tumour Trust

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 receive a minute portion 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.

A step closer...SDBTT donates 931 miles

The Samantha Dickson Brain Tumour Trust in the United Kingdom reports that in 2009 their supporters walked 931 miles for the IBTA’s Walk Around the World for Brain Tumours. One walk was undertaken by Anne and Edward Burch in memory of their daughter Susanna Twiddy who passed away from a brain tumour. Edward wrote: “Anne and I...completed the walk from Ivybridge to Lynmouth (The Two Moors Way), for which we sought sponsorship, on Saturday October 10th. The walk took 7 days carrying our packs on our backs. We, and family and friends who accompanied us for part of the way, have donated a total of 242 miles to the Walk Around the World total. It was quite a hard slog, very wet at times, exhilarating and challenging yet immensely satisfying in the knowledge that our exertions...will bring us closer [to] the day when brain tumours are curable.”
DIFFUSE INTRINSIC PONTINE GLIOMA: Collaboration is Leading to Change

By Dr Loice Swisher

It’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 followed by a relentless advancing of the disease and tragically, death months later.

Basic science research into this tumor has been frustratingly difficult. A significant hurdle has been the lack of tumor tissue on which to carry out tests.

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.

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 children die at home, far from St Jude, the emotional and logistical challenges were numerous.

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 lead to publication yet, however, The Hospital for Sick Children (“Sick Kids”) in Toronto, Canada published the first whole genomic 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

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/IBTATissueBankingPaper.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.
Kids” in Toronto has lead 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 pursuing 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 conference 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. •
Brain tumours in Lithuania

By Ugnius Smalskys and Liutauras Bycius (Kartu Lengviau)

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.

At the moment, we have only Temodal for the chemotherapeutic treatment of glioma. It is used in combination with radiotherapy in adult patients with newly diagnosed glioblastoma multiforme and later for adjuvant monotherapy.

But the main challenge confronting brain tumour patients and their relatives in Lithuania is accessing psychological and other support to help them confront the disease...

The latest treatment modes in Lithuania are being implemented slowly and there is no wider cooperation with other EU neurosurgery centers. Patients who can’t get specific efficient treatment in Lithuania could be directed to EU centers having the latest treatment facilities and competence.

Kaunas Medical University Hospital performed the first study in Lithuania which analysed patients who had a malignant glioma and received Temodal. Temodal is funded for patients by the State Patients Fund at the Ministry of Health.

After surgery, chemo-therapy/radiotherapy, patients are directed to one of the therapeutic and rehabilitation centers (sanatoriums) which are located all over Lithuania.

But the main challenge confronting brain tumour patients and their relatives in Lithuania is accessing psychological and other support to help them confront the disease, as well as live with it.

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 lot, merely vivacity and courage, but lost- is not the one who comes back Not. But one that runs, himself bandoning 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.

In 2008, “Kartu lengviau” was founded by the most active...
Lithuanian brain tumour patients and their relatives. The initiator of the organization was Ingrida Blažytė-Byčiuvienė (R.I.P), an English teacher, who fell ill with a brain tumour in 2007, at the age of 27. She struggled with the illness for two years, and she dedicated those years of her life to actively working within “Kartu lengviau”.

For numerous Lithuanian patients Ingrida became an inspiring illustration of living one’s life to the fullest and cherishing every single day of life.

“Kartu lengviau” unites brain tumour patients, their relatives, medical staff, and students. The name of the organization literally means “Easier together”. The main intention of this organization is to unify brain tumour patients and their families in Lithuania, to provide them with relevant information, with psychological and financial aid if possible, and to acquaint society with the illness by raising awareness of it.

In November 2009 Kartu Lengviau’s “The book for the patient” was published. The book covers many important topics (treatment modes, psychological aspects, advice about convalescence, etc.) for brain tumour patients and relatives.

Patients can also find all relevant information on our web site: www.kartulengviau.lt

The members of “Kartu lengviau” organize support groups for brain tumour patients and their relatives in neurosurgery centers.
I am the founder of Astro Fund, a United Kingdom charity established in April 2001 which focuses on low-grade gliomas (LGGs).

Our main focus is fundraising to support LGG research, though we also offer information on our website and support through our international internet chat 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 challenging 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 Adult Brain and CNS Rare 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 happened to be giving a lift to work that morning reached across, took control of the car and saved both their lives. To say that the seizure was out of the blue is an understatement. Within a few days we knew Paul had a brain tumour, but it was only after a biopsy that we were told that it was a low-grade brain tumour – and sent away to get on with our lives!

Devastated by the lack of support 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 wider brain tumour community, both here in the UK and of course globally as well, so I share those pressures with many others. If I can make a small difference then I have played my part, and with thousands of others each making a small difference then together we can change the world!

On a personal level, what gives me the most satisfaction from my work is talking to others and helping them to feel more positive. To have one person say that you have made them feel better is amazing - I am always very humbled by the fact that people let you into their lives and ask for help and support. It feels like a real privilege to be given 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 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! -
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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Fluorescence-Guided Resections of Malignant Gliomas using 5-ALA:
What kind of study is still necessary for determining usefulness?

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

It is now generally accepted that the greatest possible degree of safe resection is essential for survival in patients with malignant gliomas in the face of mounting evidence supporting this assumption. Strictly speaking however, this has not been demonstrated by prospective randomized trials, because trials cannot be conceived where patients are randomized to receive “complete” resections as opposed to “incomplete” resections.

Still, most surgeons attempt to resect as much of tumor as possible but are severely hampered by the fact that malignant gliomas are not easily visualized intra-operatively, even using the operating microscope. These tumors tend to blend into surrounding, frequently functional brain tissue. It is for this reason that neurosurgeons have utilized a number of tools for identifying tumor, such as neuronavigation or the intra-operative MRI. Neuronavigation however, which relies on pre-operative imaging, suffers from brain-shift once the skull is opened and parts of the tumor are resected and thus has limited usefulness in the final stages of tumor resection. The intra-operative MRI is expensive, takes time and is in general only available in highly specialized centers. Thus, a method which simply stains tumor cells intra-operatively and that could directly visualize the tumor for the neurosurgeon during surgery would be of value.

Five-aminolevulinic acid (ALA) appears to be useful in this regard. ALA is the body’s precursor in the heme biosynthesis pathway, the pathway which eventually gives rise to haemoglobin, the dye which transports oxygen in red blood cells. ALA is a small amino acid and colorless. It has been demonstrated that ALA is taken up by malignant gliomas cells and converted into protoporphyrin IX (PPIX), another metabolite in the heme biosynthesis pathway. In contrast to ALA, PPIX is highly fluorescent in the red range (Fig. 1) and therefore can be visualized by surgical microscopes which are specifically adapted to capture fluorescence. Studies have demonstrated visible fluorescence to be highly specific for tumor tissue that can be easily recognized as such by neurosurgeons. Because fluorescence can be directly visualized, fluorescence-guided resections using ALA occur in real-time without the necessity for interrupting surgery. In addition, being the body’s own metabolite, ALA is virtually non-toxic.

In Europe the benefit of ALA was demonstrated in a multicentre German trial in which patients with newly-diagnosed malignant gliomas were randomized to have surgery using traditional microsurgery or fluorescence-guided resections using ALA. All patients were treated by adjuvant radiotherapy. When surgeons were aided by ALA induced PPIX to delineate tumor, the frequency of complete resections of residual contrast-enhancing tumor was increased from 35 to 65% on early postoperative MRI. Progression-free survival was significantly improved in the group operated on using ALA whereas risks were not increased. In consequence, ALA was granted marketing authorization as Gliolan® throughout Europe in 2007.

Progression-free survival was significantly improved in the group operated on using ALA whereas risks were not increased.

In retrospect, the German study set the bar rather high in its endeavour to demonstrate a benefit from ALA. Not only was the study designed for demonstrating the efficacy of ALA for improving resections. Rather, the study was designed to demonstrate efficacy of ALA for prolonging progression-free survival. Thus, the study set out for providing evidence of clinical benefit from enhanced resections per se. Strictly speaking however, ALA is
not a therapeutic agent by its own virtue. Rather, it is an intra-operative diagnostic agent which indicates the location of residual tumor. It is up to the surgeon to utilize this method for enhancing safe resections. Thus, investigating ALA as a therapeutic agent may have been overdoing the issue, much the same as it would be if investigators were to randomize between giving contrast-enhancing agents for MRI in malignant glioma patients or not, and to see if this had any impact on survival.

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 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.

(The neither Professor Stummer, nor the IBTA, have any financial links with the makers of Gliolan, which is mentioned in this article, and whoever is the beneficiary in terms of sales will never become a millionaire but thousands of brain tumour patients could benefit by extended survival. 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.)

The Editors

Dr Salvador Villa
Dr Salvador Villa, radiation oncologist of the Institut Català d’Oncologia, has often assisted the IBTA officials in understanding complex technical questions. In this photo he is standing in front of the IBTA display at the WFNO meeting, Yokohama, Japan, in 2009.
Living in the “NOW” and not the “WHAT IF”

JOANNE 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.

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 BT’s 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.

This works both ways though, as I get an immense sense of achievement and satisfaction from doing this. I thought I was “bottom of the heap” when I had to leave work but have found inroads into having an even more satisfying job than pre-diagnosis.

Joannie McCutcheon has just celebrated her five year “tumourversary”

Brain like mine
By Joannie McCutcheon

Do you know what’s it 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
all the things I might never have finished,
To decide
who is important in my life,
To say
I love you,
TO LOVE LIFE.
My sons are my biggest support. They listen to my worries and give advice when asked. Our Neuro-Nurse at the Western General Hospital is available if I have any worries or questions.

I have used Maggie’s Centre, Edinburgh [Editors’ note: a centre for cancer patients at any stage of their journey which offers support; there are various Maggie’s Centres dotted around the UK – see www.maggiescentres.org/maggies/maggiescentres/home/home.html] and they continue to be a tremendous support to me when required. They make me feel whole and not broken.

A good friend was diagnosed last week with head and neck cancer and I took him to Maggie’s. He found the place very comforting and gained a lot from it. He has been a great support to me since my diagnosis.

I have established contacts with people with a similar diagnosis. Yes, absolutely. 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, (1) 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.
Four decades on from a malignant brain tumour diagnosis: George Plym’s amazing story

George Plym
Retired automotive technician, Founder of WNCBTS (Western North Carolina Brain Tumor Support), and brain tumour 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! I missed the ball. The next inning, a ground ball came to me and again I saw two baseballs coming at me and again I missed the 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 was a Porsche/Audi technician for 18 years. I also coached baseball.

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. [Ed: 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, family and friends is 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!

The first three things on my wish list in relation to this disease would obviously be a cure, followed by

One of the numerous MRI scans George has had over the years. This one was taken in January 2009 and shows the cavities left by resections. George has also since developed what is thought to be a meningioma and is currently on a watch and wait.

Brain tumour survivor George Plym, aged 12 in 1967, following the diagnosis of a malignant brain tumour.
a greater public awareness of the disease. Also 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 for Ever.” 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.]