2006 News & Events

December 2006: EURORDIS - the European Organisation for Rare Diseases (of which the IBTA is an associate member) is organising a digital photo contest related to the context of rare diseases. Entries close March 31, 2007. It is open to everyone. Click here for more information. Prizes will be awarded.

6 December 2006: UK MP, John Bercow, who founded the All Party Group on Brain Tumours in July 2005, was selected as the Health Champion in the UK Charity Champion Awards 2006, after being nominated by UK brain tumour charity Ali's Dream. See Awards website.

Canadian Member of Parliament Mr Bill Casey from Nova Scotia has given Notice of a debate in the Canadian House of Commons to centre around "uniform national standards and guidelines for the surveillance of all malignant and benign brain tumours, including data collection, analysis and reporting". The IBTA has written to congratulate Mr Casey on his move. A copy can be downloaded here.

16-19 November 2006: IBTA secretary Mrs Kathy Oliver attended the 11th Annual Meeting of the Society for Neuro-Oncology (SNO) at Orlando, Florida, where she received an enthusiastic response to the IBTA's plans for an International Brain Tumour Awareness Week during 21-27 October 2007, which will also include the Walk Around the World For Brain Tumours.
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Susan Sontag of the Sontag Foundation, a 12 year brain tumour survivor who spoke at the SNO conference.

Neil Levitan (the Brain Tumor Society) and Dennis Roth (TBS and the Have a Chance Foundation).

Mary Lovely (NBTF) and Kathy.

Naomi Berkowitz (ABTA) and Kathy.

Professor John Darling (UK), Kathy, Dr Gaetano Finocchiaro(Italy)

Dianne and Mike Traynor (PBTFUS) and Michelle (centre), who spoke at the conference.
15 November 2006: Mr Frank Boeye of the Belgian brain tumour support group Werkgroep Hersentumoren represented the IBTA as an observer at the General Assembly of the European Federation of Neurological Associations (EFNA) held at Brussels during 15-16 November.

November 2006: Breakthrough in Northumberland - care trust agrees to fund Temodal. View BBC story. David Hitchen, patient, was a speaker at the BTUK/IBTA/SDBTT conference last July (see below).

November 2006: A conference organised by the UK Royal Society of Medicine and entitled ‘New Developments in Research and Treatment of Brain Tumours’ will be held on Thursday 30 November 2006. It will consider a broad range of recent advances across the various differential specialities involved in the management of children and adults with brain tumours, particularly gliomas. It will emphasise the latest developments in diagnosis and multimodality treatment, particularly in the light of NICE guidelines. The objectives are to provide up-to-date information from leading authorities and to gain a greater understanding of the multidisciplinary approach used to optimise management of these tumours. Further details at: http://www.rsm.ac.uk/academ/a10-brain.htm

October 2006: The Have a Chance Walk, which was organised by Dennis and Arlene Roth of New Jersey and colleagues in The Brain Tumor Society, on Sunday 29 October, attracted 2,200 participants who raised an amazing $857,383.38 (they expect to exceed $1m) for the TBTS and the Have a Chance Foundation, for brain tumor research.

On the right hand side is a message which was sent to Dennis Roth before the walk and which he read to the participants.

Dear Dennis, Arlene and All who are organising and participating in the inaugural "Have a Chance Walk" - From Australia and the United Kingdom and places in-between, we wish you a wonderful and most successful Walk this weekend.

May the sun shine,
May the dollars pour in,
May the blisters be few,
May the walkers be many,
May the love and hope shared speed everyone on their way,
And may the cure for brain tumours be one step closer!

We'll be thinking of you all on Sunday. Good luck to everyone!

Best wishes and warmest regards, Denis Strangman, Chair, Kathy Oliver, Secretary, International Brain Tumour Alliance (IBTA)
An illustration of the worldwide partnership in sharing is the fact that the US-based The Brain Tumor Society, which organised the Walk, has assisted the research undertaken at the University of Portsmouth (UK) by Professor Geoffrey Pilkington into clomipramine and Dr Bali Rooprai into nutraceuticals. This research has also been assisted by UK-based charities, particularly the Samantha Dickson Brain Tumour Trust.

**September-October 2006:** IBTA exhibited at the 7th Congress of the European Association for Neuro-Oncology (EANO) held at Vienna during 14-17 September. The Chair later visited brain tumour support group leaders in London, Chicago, Toronto, New York, and San Francisco.

21-27 October 2007 has been chosen for the inaugural international brain tumour awareness week. Click here to download a PDF copy of a brochure about the Week which we distributed at EANO.

Kathy Oliver (Secretary, IBTA) in front of IBTA exhibit at EANO Congress in Vienna. 800 participants attended the gathering.
Kathy and Denis with Dr Graus (Spain), president of the EANO Executive Cttee, Vienna.

Rob Tufel (Ex Dir, NBTF) and support staff, San Francisco.

Zelda (L) and Carol from the Central Brain Tumor Registry of the United States, Chicago.

Henriette and Maureen, Toronto, from the Canadian Alliance of Brain Tumour Organisations.

**August 2006:** NICE cancels appeal hearing set down for 18 September to consider recommendations about therapies for patients with newly-diagnosed high grade glioma. "Miscalculation in model" discovered.

**July 2006:** IBTA Chair Denis Strangman (right) met Dr Warren Mason, Medical Director, The Gerry & Nancy Pencer Brain Tumor Centre, Toronto, Canada, at a presentation Dr Mason gave in Sydney during a short visit to Australia. The meeting was chaired by oncologist Dr Helen Wheeler (left), one of the leading brain tumour specialists and clinical trial participants in Australia.
July 2006: During 13-14 July a Joint Policy Conference involving Medicines Australia and the Department of Health and Ageing was held in Sydney to discuss the Pharmaceutical Benefits Scheme through which Australian patients are provided with subsidised drugs. The scheme currently costs $7 billion AUD. IBTA Chair Denis Strangman (right) attended as one of several invited consumer representatives and is shown in the photo with fellow committee member of Cancer Voices Australia Ms Sally Crossing (left) and Professor Lloyd Sansom (centre), Chair of the Pharmaceutical Benefits Advisory Committee, which performs a role similar to the US FDA, NZ PHARMAC, and the UK NICE.

July 2006: The International Brain Tumour Alliance (IBTA) was a co-sponsor with Brain Tumour UK and the Samantha Dickson Brain Tumour Trust of a two-day conference held at Nottingham University during 3-4 July. The conference program, which included a diverse range of speakers and topics, is available here. Kathy Oliver’s presentation is available here. On the following day brain tumour charity representatives and other interested people met with Ms Rosie Winterton, Minister of State for Health Services. Also present were Professor Mike Richards, UK National Cancer Director, Ms Sharon Hodgson MP and Mr Jeremy Wright MP, who have shown a continuing interest in the brain tumour subject.
Leaders of UK brain tumour charities in attendance at the Nottingham conference: Katie Sheen (Astro Fund), Angela and Neil Dickson (Samantha Dickson Brain Tumour Trust), Kathy Oliver (International Brain Tumour Alliance), Dr Ian Gibson MP (Chair, All Party Parliamentary Group on Cancer), Wendy Fulcher (Brain Tumour Resource Campaign), Tina Mitchell (Hammer Out), Gary Phelan (Ali's Dream), Anne Coles (Hammer Out), Ella Pybus (Brain Tumour UK), Kate Ferguson (Brainwaves NI), Sue Farrington Smith (Ali's Dream), Jenny Baker (Brain Tumour UK)

Prof Stefaan Van Gool delivered a learned paper on tumour vaccination as a new therapeutic strategy for patients with HGG.

Dijon Designs created three very striking display panels for the conference organisers and sponsors.
Three patients - David Hitchen, Diane Pearson, Frank Stuart-Brown - who spoke to participants at the Conference.

Professor Rick Kaplan, Acting Director, National Cancer Research Network (NCRN), who delivered the Peter Best Memorial Lecture 2006 "Strategies for brain tumour (and other) research in the United Kingdom and the United States".

June 2006: The IBTA has made a submission to the UK National Institute for Health and Clinical Excellence (NICE) commenting on the report of the NICE Citizens Council on the operation of the 'Rule of Rescue' in its evaluation processes. This concept relates to the possibility of special consideration for therapies for those patients who are in a life-limiting situation because of their disease.

June 2006: Comment submitted to the BBC by the Chair of the IBTA about a program "Inside the Ethics Committee" (7 June 2006) which discussed ethical issues surrounding access to unfunded new cancer therapies.

May 2006: On 13-14 May IBTA Secretary Kathy Oliver represented the IBTA at a European Cancer Patient Coalition (ECPC) advocacy conference in Milan and reports a highly successful meeting. This is a link to a media statement issued from the conference.

Some of the almost 200 delegates at ECPC 2006 participated in an enjoyable walking tour of Milan, led by ECPC President Lynn Faulds Wood (pink top, centre of picture), who is also a UK television presenter and investigative journalist and was herself diagnosed with bowel cancer a number of years ago. Others in the
The photograph include Hildrun Sundseth (ECPC Head of EU Policy, second from left); Ana Olivera (Manager of Patient Services, International Union against Cancer, UICC, front row fourth from left); Jo Grey (Chairperson, Association for Multiple Endocrine Neoplasia Disorders, back row, far right).

While in Milan Kathy met with Elisabetta and Giovanni Camporeale. Elisabetta is a seven year survivor of a GBM and Giovanni is Editor-in-Chief of the online Brainlife brain tumour medical database (www.brainlife.org) which is distributed throughout the world.

May 2006: We welcome Svenska Hjärtumörföreningen (Swedish Braintumour Foundation), a new organisation formed by Mrs Åse Rinman, whose late husband had a glioblastoma.

May 2006: The campaign to obtain a turn around of the preliminary opposition by NICE (the UK drug policy agency) to Temozolomide or Gliadel wafers for newly diagnosed patients with a high grade glioma, has intensified and has involved Denis and Kathy in a great deal of work, together with other UK-based IBTA supporters, including the IBTA's UK "hosting organisation", Brain Tumour UK. Our aim is to secure official support for these therapies so that they will be available through the NHS. Click here for a webpage detailing the campaign.

March 2006: In July 2005 IBTA Chair Denis Strangman visited Wellington, the capital of New Zealand, to help local people who were campaigning for official approval for access by brain tumour patients to Temozolomide. He accompanied several of the lobby group to see the NZ Minister of Health (see below). On 3 March 2006 the NZ drug regulatory agency, PHARMAC, announced that it had come to a provisional agreement with the distribution company to provide Temozolomide to patients with newly diagnosed glioblastomas. Not a complete success because there is no provision for patients with recurrent glioblastoma but it is a result worth noting, particularly because there are no rationing provisions, which was an outcome we feared. Congratulations to Dave and Penny Bowman and their friends. There is a link to the website for their group Head Start in the links section.
Left to right: Kathy Oliver (Secretary, International Brain Tumour Alliance), Jenny Baker (CEO, Brain Tumour UK), Ella Pybus (Brain Tumour UK), Sharon Hodgson MP (Labour, Gateshead East and Washington West) on the occasion of the All Party Parliamentary Group on Cancer’s launch (28 March 2006) at the Palace of Westminster for “A New Vision for Cancer” (see www.appg-cancer.org.uk).

25 March 2006: IBTA secretary Kathy Oliver attended a brain tumour conference in Belgium which was held at the University of Leuven.

Also attending was Mr Frank Boeye (centre, below) founder of Werkgroep Hersentumoren, which is a newly established brain tumour patient and carer support group in Belgium. Left - Marie-Jeanne Vansteenkiste (Treasurer); Right - Lia Le Roy (Secretary).

Kathy Oliver is on the left of photo. In the middle is Dr Nina De Klippel, neurologist in the Virga Jesse Hospital in the city of Hasselt (University of Limburg). On the right is Professor Dr. Sebastian Engelborghs of the University of Antwerp. Kathy was able to tell the assembled participants about the work of the IBTA. All conference participants received a package of IBTA materials.
Professor Dr. Peter De Deyn, the chairman of Vlaamse Vereniging voor Neurologie (Flemish Association of Neurologists), and also the president of the Belgium conference.

Kathy Oliver represents IBTA at Italian brain tumour conference -

On 27 January 2006 IBTA Secretary Mrs Kathy Oliver was invited to deliver a presentation about the IBTA to a prestigious brain tumour conference held at L'Aquila, Italy, which was organised by Dr Italo Scotti (seated on right).
Some of the speakers at the L'Aquila conference, which included Francesca Scropetta, who founded an Italian brain tumour organisation in honour of her son, Mike Traynor (USA, red coat), Prof Stefaan Van Gool of the Gasthuisberg Hospital, Catholic University of Leuven, Belgium (white shirt, front), and Dr Giovanni Gaviraghi of Siena Biotech (on the far right). Other people in the photograph are members of Fabrizio Scotti's family. Fabrizio is the man in whose memory the L'Aquila conference was held and who inspired his brother, Dr Italo Scotti, to found Il Fondo di Fabrizio which raises money for brain tumour research in Italy.

Kathy Oliver is in the front row and next to her is Dr Marina Bentivoglio who has just been elected Secretary-General of the International Brain Research Organisation and will take up her post in January 2007.

Mike Traynor, President of the Pediatric Brain Tumor Foundation of the US (PBFTUS), gave an excellent presentation at L'Aquila on the activities of his organisation which this year raised $4.1 million for pediatric brain tumour research.

On 10 February 2006 IBTA Chair Denis Strangman (far right) was invited as a consumer (patient/carer) representative to attend the inaugural meeting in Sydney of the Australian Working Party for the Development of Clinical Practice Guidelines for the Management of Adult Malignant Brain Tumours. The meeting was attended by a number of Australia's leading neurosurgeons and neuro-oncology specialists.
Notes: IBTA is aware that in the United States "tumour" is spelled "tumor" and will use that spelling for printed materials directed to that region. It was also the intention of the founding meeting that we seek to represent all tumours of the central nervous system. As is the practice in the scientific literature and clinical use, we use the words "brain tumour", not "brain cancer".