

**15 December 2008:** The IBTA was represented at the **SNO scientific conference** held at Las Vegas during 20-23 November. A number of other patient and caregiver groups were also present, including ABTA, NBTS, PBTF, the Tug McGraw Foundation and CBTF, together with individual advocates such as Susan Marshall (BTFC) and Pam del Maestro (CABTO).



IBTA Chair Denis Strangman with Professor Takamitsu Fujimaki (Japan) who is the Secretary-General of the [3rd Quadrennial Meeting](#) of the World Federation of Neuro Oncology to be held in Yokohama, Japan in May 2009.



Rob, Sharon and Joanne from the California-based Ben and Catherine Ivy Foundation, which funds brain tumour research.



Denis with PLGA representative and Joseph B. Fay, Executive Director of the New York-based CBTF.

**The latest IBTA E-News** is available from the Newsletter link at the left. These are hyper-links relevant to the content of the Newsletter: Al Musella's oligodendroglioma research fund: <http://virtualtrials.com/oligofund/> IBTA submission to NICE consultation on End of Life medicines: <http://www.theibta.org/EndOfLifeSubNICE.pdf> Article in French about the IBTA: <http://www.theibta.org/AORTICFrenchArticle.pdf> Media release of Mike Ferguson's article about Katja's Walk: <http://www.theibta.org/KatjaWalk.pdf> Hanneke Zwinkels article about the neuro-oncology nurse: <http://www.theibta.org/ZwinkelsArticle.pdf> IBTA Avastin Review: <http://www.theibta.org/AvastinReview.pdf> SNO Outreach Presentation: <http://www.theibta.org/OutreachPresentationText.doc> Lloyd Morgan handout re pediatric initiative: <http://www.theibta.org/BilovskyHandout.doc> Cancer Institute NSW Fact Sheets for brain tumour patients: [http://www.cancerinstitute.org.au/cancer\\_inst/patients/](http://www.cancerinstitute.org.au/cancer_inst/patients/) Link to the new Brain Tumour Alliance Australia organisation: <http://www.btaa.org.au> Health technology assessments paper: <http://www.theibta.org/HTAToolKit.pdf>

**18 November 2008:** The IBTA announces the dates for the 2009 International Brain Tumour Awareness Week. Following a survey of supporters the majority of respondents have indicated that **Sunday 1st November 2009 - Saturday 7th November 2009** is the most suitable time for the Awareness Week in 2009. Click [here](#) for further details of survey results.

**6 November 2008:** 28,618 walkers in over 100 separate walks in 15 different countries in North and South America, Europe and Asia, have so far reached a combined total of 123,024 kms in the Walk Around the World for Brain Tumours with more results still to arrive. Our target was three times around the World at the Equator (120,000 kms). During the recently completed International Brain Tumour Awareness Week (26 October to 1 November) dozens of seminars, education days, picnics and gatherings were held around the world to help raise awareness about the specific challenges of brain tumours. Reports of events held can be accessed [here](#) and

[here](#).

**29 October 2008:** The 2008 Awareness Week has been proceeding well. A [media release](#) has been distributed widely and the webpages for [proposed](#) and [completed activities](#) have been updated as organisers report in about their events. A new translation for the [German poster](#) has also been uploaded to the posters webpage.

**16 October 2008:** The latest IBTA E-News has been uploaded. Click [here](#) to read it. The IBTA, in association with Meningioma UK and the United Brain Tumour Campaign (UK), has made a submission to the NCIN/onCoreUK/NCRI consultation on [Access to Samples and Data for Cancer Research](#), in which we have recommended that patients who request it be given access to any of their own genetic information identified as a result of donating tumour or blood samples for research. The submission may be downloaded from [here](#).

**21 September 2008:** The IBTA had an exhibition booth at the recent Conference of the European Association of Neuro Oncology (EANO), held in Barcelona. A copy of the IBTA's 92-page book about the international awareness-raising activities held in 2007 was distributed to each of the participants and was very well received. IBTA secretary Kathy Oliver spoke about the brain tumour journey at a pre-conference MAP satellite seminar.



The IBTA exhibition booth at the EANO Conference.

Exhibiting at these conferences enables the IBTA to promote its international brain tumour awareness raising projects.



Kathy Oliver presents at the MAP seminar with Dr Michael Weller (Switzerland) chairing. Lia and Lisette from the Belgian brain support group [Werkgroep Hersentumoren](#) also attended the Seminar. Ase Rinman from the Swedish brain tumour patient support group [Svenska hjärntumörföreningen](#) was also present at the EANO meeting.



Kathy with Professor Takamitsu Fujimaki (Japan) who is the Secretary-General of the [3rd Quadrennial Meeting](#) of the World Federation of Neuro Oncology to be held in Yokohama, Japan in May 2009.



IBTA supporter Dr Andrea Pace (Italy) on the left, Kathy Oliver, centre. In the background is Ingrida Blazyte-Byciuvienė, a brain tumour survivor from the Lithuanian group [kartu lengvian](#) who assisted Kathy on the IBTA booth.

**7 September 2008:** The IBTA participated as an Associate Member Organisation at the World Cancer Congress

organised by the International Union Against Cancer ([UICC](#)) in Geneva during 27-31 August. On his return to Australia IBTA Chair Denis Strangman stopped in Singapore to meet with the local brain tumour support group.



The IBTA had a panel display at the Congress. On one side was the Catalan Institute of Oncology and on the other the International Psycho Oncology Society.



Kathy Oliver (Secretary, IBTA) and Denis Strangman (Chair IBTA) met with Congress delegates from Nepal.



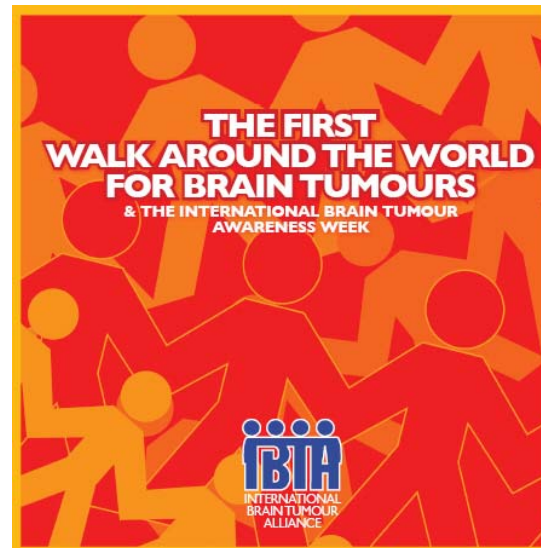
IBTA Chair Denis Strangman gave a presentation about the work of the IBTA to the Singapore brain tumour support group.



Dr Keith Lim Hsiu Chin (Radiation Oncologist, Tan Tock Seng Hospital) and Emily Ang LiLing (Senior Staff Nurse, National Neuroscience Institute).

**22 August:** IBTA Chair Denis Strangman issues a [media statement](#) on new statistics for cancer in Australia which show continuing poor survival figures for brain tumour patients and calls for more research and support.

**8 August 2008:** The IBTA has produced a 92-page book commemorating the awareness raising activities undertaken by brain tumour and cancer organisations around the world during 2007. A free copy is available to brain tumour patients, caregivers and family, depending on the IBTA's resource capacity and supplies. Click [here](#) for further information.





Seamus and Eileen Feely from Chicago helped Sally Payne (Australia) staff the IBTA booth.

**12 June 2008:** The IBTA had an exhibit booth at the ASCO scientific meeting held at Chicago during 30 May - 3 June. Sally Payne (Australia) has prepared a brief overview of the key points from the CNS presentations which can be accessed [here](#).

**22 May 2008:** Following news of US Senator Ted Kennedy's diagnosis of a malignant primary brain tumour the IBTA released a statement to the international media which may be accessed [here](#).

**20 May 2008:** The IBTA has today distributed to the main English-language brain tumour patient discussion groups a memorandum about pseudo progression in glioblastoma multiforme brain tumour patients. A copy may be downloaded in PDF format from [here](#). This phenomenon may lead to premature cessation of temozolomide treatment for some patients, who could then experience an unfortunate outcome.

**10 May 2008:** 132 brain tumour and cancer related organisations support the International Brain Tumour Awareness Week (26 October - 1 November) and the Walk Around the World for Brain Tumours.

**7 May 2008:** The International Brain Tumour Alliance is now three years old and has exceeded the expectations of those who established it. The IBTA exhibits regularly at scientific conferences, creates opportunities for awareness-raising, and advocates for brain tumour patients and caregivers in a variety of forums.

### **Supporting organisations now stands at 117 (22/03/08)**

The number of brain tumour patient support and advocacy groups, and research and scientific bodies who support the IBTA's Walk Around the World for Brain Tumours and the International Brain Tumour Awareness Week (26 October - 1 November) has grown to 117. [\[more...\]](#)

### **SDBTT Astro Fund Brain Tumour Information Day (18/03/08)**



The IBTA Secretary Kathy Oliver gave a presentation to the SDBTT Astro Fund Brain Tumour Information Day in London on 17 March 2008, under the title “Hope for the Future: Alliances and Promising Areas of Research”.

*Pictured here, left to right, are Professor Geoff Pilkington (University of Portsmouth), Kathy, Neil Dickson and Angela Dickson, founders of SDBTT*

[\[more...\]](#)

### **Article in European magazine (18/03/08)**

The IBTA Secretary Kathy Oliver has had an article published in a special edition of "Parliament Magazine", devoted to cancer, and distributed to Members of the European Parliament and elsewhere. [\[more...\]](#)

**Hammer Out patient/carer conference, Devon, UK (11/03/08)**



The IBTA Secretary, Kathy Oliver (left of photo), attended the Hammer Out Patient/Carer conference near Exeter, Devon, on 8th and 9th March, 2008 where she gave a presentation on "Hope for the Future and Promising Areas of Research".

[\[more...\]](#)

**NICE and the Rule of Rescue (09/03/08)**

The IBTA has lodged a submission to the UK NICE (National Institute for Health and Clinical Excellence) protesting at NICE's rejection of the "Rule of Rescue" in the "Consultation on draft second edition of social value judgements: principles for the development of NICE guidance" document. [\[more...\]](#)

**Australian Genomics and Clinical Outcomes of High Grade Glioma meeting (09/03/08)**

The Chair of the IBTA, Denis Strangman, was invited to make a presentation to the Strategic Planning Meeting of the Australian Genomics and Clinical Outcomes of High Grade Glioma (AGOG) group in Sydney on 6 March 2008.



[\[more...\]](#)

**[Brain tumour conference at Bologna](#) (01/03/08)**



IBTA

secretary Mrs Kathy Oliver attended the IV International Conference on Future Trends in the Treatment of Brain Tumours held at Bologna, Italy, 22 - 23 February, 2008 [\[more...\]](#)

**[1st European Rare Disease Day](#) (27/02/08)**

Friday 29 February has been chosen as the First European Rare Disease Day. The IBTA has issued a statement. [\[more...\]](#)

**[British Journal of Neuroscience Nursing](#) (22/02/08)**

An article about attendance at the nurses' special meeting at last year's SNO conference, written by IBTA Secretary Kathy Oliver, has been published in the latest issue of the [British Journal of Neuroscience Nursing](#). [\[more...\]](#)

**[World Cancer Day](#) (02/02/08)**

Monday 4 February 2008 is World Cancer Day. The IBTA has distributed a media release to draw attention to the need for special attention for brain tumours.

[\[more...\]](#)

**[SNO Conference 2007](#) (13/01/08)**

A report by Kathy Oliver (IBTA Secretary) of the October 2007 Society for Neuro-Oncology (SNO) conference has been uploaded to the IBTA website. [\[more...\]](#)

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