

IBTA magazine: We are reasonably confident that copies of the IBTA's "Brain Tumour" magazine have now been distributed to recipients in the 106 countries where we have contacts, with Spain and Australia being the last countries to be covered; however, if you have not received a copy by now please go to this [link](http://emailcontrol.com.au/link.php?M=12640966&N=31282&L=35695&F=H) and complete the on-line form. Reaction to the 2012 magazine has been encouraging. See this [link](http://emailcontrol.com.au/link.php?M=12640966&N=31282&L=42269&F=H) for readers' comments.

800 copies were distributed at the very successful ISPNO (International Symposium on Pediatric Neuro-Oncology) conference held recently in Toronto, Canada. The 602 research abstracts presented to ISPNO have been published under 18 categories in a [supplement](http://emailcontrol.com.au/link.php?M=12640966&N=31282&L=42300&F=H) to the June issue of the journal *Neuro-Oncology* and for the idly curious here is a [link](http://emailcontrol.com.au/link.php?M=12640966&N=31282&L=42286&F=H) to over 100 photographs taken at the conference by the official photographer.

Experimental furore: A large amount of publicity has been generated by a case in the USA involving two UC Davis neurosurgeons who introduced pathogenic bacteria into the craniotomy wounds of several brain tumour patients as part of an experiment. The [story](http://emailcontrol.com.au/link.php?M=12640966&N=31282&L=42276&F=H) in the *Sacramento Bee* newspaper appears to be the most extensive report and this is a [link](http://emailcontrol.com.au/link.php?M=12640966&N=31282&L=42305&F=H) to a video of a news report about the case. Even *Nature* magazine bought into the [debate](http://emailcontrol.com.au/link.php?M=12640966&N=31282&L=42281&F=H). The Chair of an Institutional Review Board (IRB) appears to have played an important pro-active role and the episode is a salutary reminder of the need for appropriate review and oversight of clinical research, not just by members of an IRB, but also of the need to involve patient advocate representatives relevant to the area of research.

ASCO: As reported last month, attendance at this year's ASCO meeting appeared to be down on the 2011 figures. This has been confirmed in an [analysis](http://emailcontrol.com.au/link.php?M=12640966&N=31282&L=42306&F=H) of attendee demographics which showed there were 31,250 registrants (2012) compared with 31,800 (2011) but it remains the largest international oncology meeting of its type. International attendees still constituted the majority at 52%.

Dr Susan M Chang, who authored the Timeline of brain tumor treatment developments reproduced in the IBTA's *Brain Tumour* magazine, has produced an audio [Cancer.net](http://emailcontrol.com.au/link.php?M=12640966&N=31282&L=42295&F=H) podcast, under the aegis of ASCO, which summarises research findings for brain tumours arising from the 2012 ASCO Conference. Dr Chang will visit Australia in August to speak at the MOGA and COGNO [ASM's](http://emailcontrol.com.au/link.php?M=12640966&N=31282&L=38174&F=H) and a [Forum](http://emailcontrol.com.au/link.php?M=12640966&N=31282&L=42271&F=H) for patients and families organised by [BTAA](http://emailcontrol.com.au/link.php?M=12640966&N=31282&L=42297&F=H).

New European clinical trials regulation:

The European Commission has finally published (on 17 July) its proposal for a Regulation of the European Parliament and of the Council on clinical trials on medicinal products for human use. The new Regulation repeals the highly controversial EU Clinical Trials Directive 2001/20/EC which was criticised for hindering clinical research across Europe because of its complex red tape. The Regulation will impact on the conduct of clinical trials for brain tumour patients. For example, Article 9.3 states that "the view of at least one patient shall be taken into account" in the assessment process. Additionally, the bureaucratic administrative burden attached to submitting clinical trial proposals for assessment and evaluation has become more streamlined. The IBTA signed a joint statement organised by Cancer Research UK to support the proposal for a revision to the original Directive.</p> <p>Dianne Traynor: The

IBTA was shocked and saddened to learn of the death last week of Dianne Traynor, President and Chairman of the Board of the Pediatric Brain Tumor Foundation (PBTf) in the USA. The PBTf has supported basic, translational and clinical research at more than 50 institutions around the world. We extend our deepest condolences to Dianne's family, friends and PBTf colleagues on the loss of such an amazing, dynamic and inspirational woman. This is a link to an article that Dianne wrote for the 2010 IBTA <i>Brain Tumour</i> magazine describing her work.</p> <p>Deadlines: The deadline for applications for the eight regional-based \$2000 scholarship s offered by the Society for Neuro-Oncology (SNO) for attendance at the SNO conference in Washington in November by those who work and live outside North America, is 10 August. The deadline for late-breaking abstract > submissions for the meeting of the European Association of Neuro Oncology (EANO) in Marseille in September, is 28 July and normal rate registration is possible until 31 July. Alex's Lemonade Stand Foundation has announced plans to release \$10m in funding for pediatric cancer research and there are various deadlines for different categories. Applications for nurse researcher grants are currently open and close on 1 August. The deadline for a patient-oriented EORTC one-day seminar > on clinical trials to be held in Brussels on 13 September, is 31 August.</p> <p>To tell or not to tell: A UK couple has revealed > that they deliberately withheld information from their twelve-year-old child that his inoperable brain tumour was terminal. After the child passed away in May his heartbroken family was consoled by the knowledge that Adam (the child) was never depressed about the knowledge of his imminent death. This is a difficult subject and in some cultures families actually request doctors not to tell the patient (usually an adult) that they have a terminal illness such as a brain tumour. Meanwhile, a nine-year-old boy with an inoperable brain tumour and very poor short-term memory, also from the UK, uses a

"SenseCam" camera hanging from his neck to help him remember what he has been doing each day. The camera automatically takes 2,000 pictures per day which can be retrieved to jog his memory.

Medulloblastoma: A collection of articles about ground-breaking research into the childhood brain tumour medulloblastoma appeared in the journal *Nature* during July. Two of the articles are available on Open Access: [here](http://emailcontrol.com.au/link.php?M=12640966&N=31282&L=42283&F=H) and [here](http://emailcontrol.com.au/link.php?M=12640966&N=31282&L=42284&F=H).

An [abstract](http://emailcontrol.com.au/link.php?M=12640966&N=31282&L=42282&F=H) is available publicly for one other article. Generally, the research identifies potential biomarkers and gene mutations and indicates therapeutic opportunities and, hopefully, could lead to more targeted treatments. The research included the study of preserved brain tumours from 1,000 children.

MDxHealth and Merck KGaA: MDxHealth SA has [announced](http://emailcontrol.com.au/link.php?M=12640966&N=31282&L=42285&F=H)

[an expanded collaboration with Merck KGaA for the development and worldwide commercialisation of MDxHealth's MGMT diagnostic test PredictMDxTM for glioblastoma.](http://emailcontrol.com.au/link.php?M=12640966&N=31282&L=42285&F=H) Merck Serono is developing its therapy cilengitide for use with standard therapy for newly diagnosed glioblastoma patients.

Lucathone: Spectrum Pharmaceuticals Ltd has [initiated](http://emailcontrol.com.au/link.php?M=12640966&N=31282&L=42303&F=H) a placebo-controlled Phase II clinical trial of lucathone together with standard therapy, for glioblastoma. Lucathone is "An orally administered small molecule (which) inhibits topoisomerase II and AP endonuclease and has been shown to sensitize tumor cells to radiation and chemotherapy by inhibiting DNA repair." The trial will take place in multiple sites in the USA and India. Meanwhile, a [study](http://emailcontrol.com.au/link.php?M=12640966&N=31282&L=42304&F=H)

by the Drug Information Association, based around query rates, [suggests that the quality of clinical trials conducted in emerging countries is consistent with those conducted in developed regions](http://emailcontrol.com.au/link.php?M=12640966&N=31282&L=42304&F=H). Acknowledgement was made of several limitations in the analysis.

DCVax-L immune therapy: Northwest Biotherapeutics [announced](http://emailcontrol.com.au/link.php?M=12640966&N=31282&L=42279&F=H)

[that its German partner Fraunhofer IZI has received official approval and certification from the regional and national regulatory agencies for the manufacture of its DCVax immune therapy for glioblastoma patients.](http://emailcontrol.com.au/link.php?M=12640966&N=31282&L=42279&F=H)

Discriminatory attitude: Speaking during a (US) House Rules Committee debate on the GOP's bill repealing the Affordable Care Act, [Representative David Dreier](http://emailcontrol.com.au/link.php?M=12640966&N=31282&L=42299&F=H) (R-CA) said that someone diagnosed with a brain tumor should not have health care provided. He added [I do believe that there can be a structure to deal with the issue of pre-existing conditions](http://emailcontrol.com.au/link.php?M=12640966&N=31282&L=42299&F=H). Until they reveal themselves, usually by some catastrophic event, it is ridiculous to categorise a brain tumour as a [pre-existing condition](http://emailcontrol.com.au/link.php?M=12640966&N=31282&L=42299&F=H) in this context and in the way that some parsimonious travel insurance companies have.

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Boswellia: We are aware that boswellia is used extensively in Germany and some other countries as an anti-inflammatory and dexamethasone (Decadron)-sparing therapy. A health professional has asked the IBTA for the best available English-language research involving boswellia and brain tumours. If you can assist please email: chair@theibta.org

Fusion of two adjacent genes: Scientists have discovered that in a sub-set of glioblastoma some cases are caused by the fusion of two adjacent genes. In mouse studies they found that drugs that target the protein produced by the fusion can dramatically slow growth. See also.

Indonesia: In a news report about the relatively novel introduction of a Gamma Knife machine in Indonesia it was mentioned in passing that there are about 8,000 brain tumour cases per year in the country and there are only 206 registered neurosurgeons.

Rare genetic variant in Glioma: Researchers have validated a link between a rare genetic variant (rs78378222) and the risk of glioma and identified an association between the variant and improved rates of survival. See also.

Laser system for neurosurgery: A European Union-funded project (the MIRSURG project) has developed a table-top all-solid-state prototype laser source which enables minimally invasive neurosurgery by emitting an optical wavelength of 6.45 microns which is said to result in reduced collateral damage.

Avastin injection into the brain: A three year malignant brain tumour survivor from a Phase 1 trial at Weill Cornell Brain and Spine Centre which involves intraarterial intracranial infusion of Avastin into the patient's brain appeared recently on television and seems to be doing well.

Toca 511: MRI Interventions, Brainlab AG and Tocagen will align in utilising the ClearPoint Neuro Intervention System at selected sites involved with Tocagen's clinical trial of the delivery of Toca 511 for brain tumours. Meanwhile, the Musella Foundation has awarded a grant to Tocagen to assist with the on-going clinical trial of Toca 511 and Toca FC for recurrent high grade glioma.

ALD-451: Cytomedix has announced the initiation of a Phase 1 clinical trial involving ALD-451 for glioma patients in collaboration with Duke University Medical Centre. ALD-451 is "the population of autologous pluri-potent ALDHbr stem cells isolated from the patients' bone marrow using Cytomedix'

proprietary technology". The trial will also seek an initial description of the effects of the drug on neuro-cognition.

PET imaging agent: Novelos Therapeutics has successfully [dosed](http://emailcontrol.com.au/link.php?M=12640966&N=31282&L=42280&F=H) three patients in a Phase 1-2 PET imaging trial of 1-124-CLR1404 (LIGHT) in patients with primary or secondary brain tumours. The sponsors are hopeful that their imaging agent will supplant FDG in clinical use.

ImmunoCellular: ImmunoCellular Therapeutics made several [announcements](http://emailcontrol.com.au/link.php?M=12640966&N=31282&L=42287&F=H) in July - (1) The FDA has approved a physician-sponsored investigative new drug (IND) Phase 1 clinical trial of ICT-121 a dendritic-cell-based vaccine targeting CD-133 in recurrent GBM patients. This is different from its first vaccine ICT-107. (2) The Company will expand its current Phase IIb trial of ICT-107 in GBM patients who are HLA-A1/A2 positive, from 102 to 123 patients. (3) The Company announced the allowance of a Japanese patent relating to its technology for these therapies.

Rare Cancers EU Access Index: Because primary brain tumours are defined as a rare cancer, the IBTA is a partner in the [title="blocked::http://www.rarecancerseurope.org/"](http://www.rarecancerseurope.org/) [Rare Cancers Europe](http://emailcontrol.com.au/link.php?M=12640966&N=31282&L=42277&F=H) (RCE) multi-stakeholder initiative. We would be grateful if readers of the IBTA e-news *living in the EU27 countries* could answer some questions about access to rare cancer care. Your answers will help to lay the foundation for the first-ever Rare Cancers EU Access Index, comparing rare cancer care and policies across the European Union. The survey, which will close on 16 September 2012, is conducted with the help of the [title="blocked::http://www.ihe.se/start-2.aspx"](http://www.ihe.se/start-2.aspx) [Swedish Institute for Health Economics](http://emailcontrol.com.au/link.php?M=12640966&N=31282&L=42288&F=H). To take this 10-15-minute survey, please click on the following [link](http://emailcontrol.com.au/link.php?M=12640966&N=31282&L=42263&F=H).

International survey on Pathology in Rare Cancers: In addition, RCE and the European Society of Pathology (ESP) have jointly launched an international survey on Pathology in Rare Cancers. All healthcare professionals from around the world working in pathology are invited to participate in this survey (which closes on 31 October 2012) by completing a short online questionnaire [here](http://emailcontrol.com.au/link.php?M=12640966&N=31282&L=42272&F=H).

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Thank you for your continuing support.

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