

Dear Friend

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**ASCO:** The Annual Scientific Meeting of the American Society of Clinical Oncology (ASCO) will be held during 1-5 June at Chicago. There are 231 abstracts with the keyword "CNS" in their title. Click [here](#) for access to the list. This is [a link](#) to the CNS sessions. The IBTA will have a presence in the ASCO Patient Advocacy booth (No 3005 - see [here](#) for map) and will have copies available of the just-published 2012 edition of "Brain Tumour" magazine (see below).

**IBTA magazine:** 12,000 copies of the 2012 edition of "Brain Tumour" magazine have been printed in the UK ready for free worldwide distribution to recipients in 106 countries. This 140-page publication contains over 80 interviews, articles and reports of broad interest, plus a special A2-size wall chart/poster of progress in brain tumour treatments prepared originally by Dr Susan M Chang for ASCO in an on-line format. Copies of the magazine will be posted from Europe to all those for whom we have a postal/land address. If you do not receive your copy by early July, please convey your details via this [on-line form](#) .

**EU Access Index:** [Rare Cancers Europe](#) aims to develop by the end of this year a Rare Cancers EU Access Index, measuring access to rare cancer treatment and care in the 27 EU Member States. The index will include data on a pre-defined set of indicators and will help to better assess and compare the situations in individual countries. Of the seven rare cancer types selected for the pilot study, paediatric and adult central nervous system (CNS) tumours are two of them.

**PNET tumours:** US researchers have [identified](#) a possible connection between mandated folic acid fortification of foods and a reduction in the incidence of PNET (primitive neuroectodermal tumors).

**Twins:** An adult Australian who was suffering from persistent headaches [convinced](#) his

identical twin brother (who was not experiencing headaches) to have an MRI during which a 4 cm brain tumour was discovered in the base of the brother's skull (i.e. the twin who had no symptoms). Doctors are puzzling over the connection.

**Long term brain tumour survivors:** The recently published IBTA magazine contains a story based on interviews with two long-term GBM survivors. This is a subject of particular interest to Dr Virginia Stark-Vance from Texas (email: vistark@att.net) who intends to look at long term survivors from among those with PCNSL, anaplastic astrocytoma, or glioblastoma brain tumours.

**Xerecept:** Celtic Pharma has [announced](#) that it will present the findings from a Phase I/II study of Xerecept for paediatric neuro oncology patients at the International Symposium for Paediatric Neuro-Oncology (ISPNO) meeting in Toronto during 24-27 June. Xerecept is a dexamethasone-sparing alternative. There have also been talks with the FDA about a follow-up study. It may also be relevant for the adult brain tumour population and is at a Phase III stage for that group. It is a pity that there is not a similar manufacturing imperative for trials to be instigated of boswellia as a dexamethasone-sparing supplement or substitute. The IBTA will have a presence at the ISPNO meeting.

**British Prime Minister:** The British Prime Minister Mr David Cameron [sent](#) a hand-written response to a UK couple who lost their young daughter to a brain tumour and who had approached him to support more funding into the causes of brain tumours. Mr Cameron referred to the death of his own son, Ivan, from cerebral palsy who he "misses every day".

**DCVax-L immune therapy:** Northwest Biotherapeutics has [advised](#) that it now has 41 US clinical sites for the trial of its immune therapy for GBM tumours and plans to have 60 sites in the US and Europe by late 2012. The FDA has accepted an amendment of the trial, which is now designated as a Phase III trial. Earlier in May it [announced](#) that it had received a grant of \$5.5 m from the German Saxony Development Bank for 50% of the costs for manufacturing in Germany and for its GBM trial to include 30 clinical sites in Germany.

**Melanoma metastases:** A [report](#) published in the *Lancet* of a dose escalation study for dabrafenib used in people with melanoma and brain metastases showed that nine of ten patients had a reduction in the size of their brain lesions but the tumours did eventually

[progress](#)

**NovoTTF therapy:** The [European Journal of Cancer](#) has published the results of a phase III study of the use of Novocure's NovoTTF therapy in recurrent glioblastoma, comparing it with physician's chemotherapy choice. The authors concluded: "No improvement in overall survival was demonstrated, however efficacy and activity with this chemotherapy-free treatment device appears comparable to chemotherapy regimens that are commonly used for recurrent glioblastoma. Toxicity and quality of life clearly favoured TTF." In mid-May the company announced the launch of a dedicated US-focused

[website](#)

for the use of the therapy for recurrent glioblastoma

**Genetic causes of GBM:** [According to](#) Dr Michael Berens (Director of the Translational Genomics Research Institute - TGen - Cancer and Cell Biology Division) a \$4.5 m grant from the US National Institute of Health to a multidisciplinary search led by TGen will help "... mine vast amounts of data to come up with possible cancer vulnerabilities and the most promising ways to attack GBM".

**Wrong operation:** A former paramedic has been [awarded](#) a seven figure sum after a Coventry (UK) surgeon removed the wrong part of his brain in an operation intended to remove a brain tumour which, on later analysis of the patient's blood test results, did not need removal and could have been managed with medication.

**Paediatric brain tumours and diversity:** According to an [article](#) in *Cancer Cell* paediatric brain tumours preserve specific characteristics of the normal cells from which they originate and are more diverse than previously believed.

[Identification](#)

of the origin of the tumour may help to develop better markers and treatment options.

**Glioblastoma cell migration:** Researchers at John Hopkins (USA) have [identified](#) the protein NKCC1 as assisting in the migration of glioblastoma cells and have slowed its migration in laboratory experiments using the diuretic bumetanide.

**NeuroBlate System:** Monteris Medical has [secured](#) \$9m funding to further develop its NeuroBlate System (formerly AutoLITT) in North America. The system is used for MRI guided neurosurgical ablation of brain tumours.

**P140K:** In a small experiment involving only three glioblastoma patients US researchers have [found](#) that "transplanted P140K-expressing hematopoietic stem and progenitor cells are chemoprotective, potentially maximizing the drug dose that can be administered."

**ICT-107:** ImmunoCellular Therapeutics will have two posters at the ASCO conference in Chicago reporting on its ICT-107 therapy for brain tumours. In an investor-related [interview](#) on 10 May the CEO Dr Manesh Singh said that the company might reveal more information about its brain tumour trial "in the next few weeks".

**Ketogenic diet:** Dr Adrienne Scheck and colleagues from the Barrow Neurological Institute (USA) have authored an [article](#) which found in animal studies that a ketogenic formula KetoCal (KC) "suggests that cellular metabolic alterations induced through KC may be useful as an adjuvant to the current standard of care for the treatment of human malignant gliomas".

**Generic temozolomide:** The Mumbai-based generic drug producer Cipla has [reduced](#) the price of its Temoside brand of temozolomide.

**Avastin:** Taiwan's Bureau of National Health Insurance has [decided](#) to cover the cost of Avastin for brain tumour patients. Meanwhile, a US researcher has [found](#) in a small study that there could be a correlation between the use of Avastin for recurrent GBM and the risk for secondary gliosarcoma.

**Misdiagnosis:** According to a media [report](#) "A teenage girl with a brain tumour the size of a golf ball was repeatedly turned away by doctors who told her she was just homesick. Megan Thomson, 20, had just begun a course at Leeds Metropolitan University when she presented herself to doctors complaining of headaches and trouble walking. Megan's symptoms worsened

as she was repeatedly told by doctors she was homesick, stressed or partying too hard."

**Film and Video:** A film about a man's battle with a brain tumour "Stopped on Track" [won](#) the best film award at the German Lola-Gala in Berlin. In a 30-minute

[video story](#)

about his own brain tumour experience UK resident Peter Wilkinson talks about the need for more research and lobbying and greater awareness. Brain Tumour Alliance Australia has uploaded to You Tube

[presentations](#)

made at a recent brain tumour forum held in Sydney.

Thank you for your continuing support.

[Denis Strangman](#) (Chair and Co-Director)

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