

Dear Friend

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IBTA Magazine: The worldwide distribution of the IBTA's "Brain Tumour" magazine is in progress with individual copies having already been received in Canada, the USA, UK and Ireland. It is a major undertaking but if you do not receive a copy by about mid-July please register your land/postal details [here](#) .

ASCO: The IBTA distributed 250 copies of its magazine at the ASCO conference held recently in Chicago and were ably assisted at our stand in the Patient Advocacy booth by locals Mary Ellen Maher and Jean Arzbaecher. Demographics of who attended the ASCO meeting are not yet available but based on last year's [analysis](#) there were probably fewer overall attendees and consequently fewer present in 2012 equivalent to the approximately 774 professionals who indicated last year that they had an interest in CNS tumours.

In the presentations, posters and abstracts, attention was given to the results of the EORTC study of patients with anaplastic oligodendroglial brain tumours which showed a survival benefit for those receiving chemotherapy (procarbazine, lomustine, vincristine) after radiation therapy, particularly those with a 1p/19q co-deletion. Also attracting attention were the results of the German NOA-08 trial of GBM or AA patients over 65 years of age. Temozolomide (TMZ) demonstrated non inferiority to radiation therapy (RT) in the overall population. For those with MGMT promoter methylation outcomes were better for TMZ versus RT. A commentator on the results suggested: "I would argue strongly that if you don't have MGMT results, you should not give temozolomide upfront". (See Page 15A [here](#) .) The IBTA, as a patient advocacy group, has some doubts about such an approach.

There was also general [interest](#) in Immunocellular Therapeutics' ICT-107, for which a Phase IIb trial is underway and in Tocagen's [therapy](#) . Among the posters there was interest in the first clinical presentation about Apogenix's [APG101](#)

PhRMA Medicines in Development - Brain tumours: In its annual [report](#) on new therapies being developed by the pharmaceutical industry the US PhRMA organisation lists 62 for brain tumours (some in conjunction with other tumours), compared with 121 for lung cancer and 120 for leukaemia. The therapies listed are those initiated by the pharmaceutical industry and do not include investigator-led studies initiated by researchers and clinicians in hospitals and other institutions.

Conferences: IBTA co-director Kathy Oliver co-chaired with Gemma Gatta (INT Milan) a session on the [RARECARENet Project](#) at the recent ECPC (European Cancer Patient Coalition) [Masterclass](#) in Reiti, Italy. Following the Rieti Masterclass Kathy is also attending the first ever chordoma patient meeting in Amsterdam after which there is a treatment conference. Any of our readers with a particular interest in chordomas could contact

[Kathy](#)

. The IBTA will also have a presence at the British Neuro Oncology Society [conference](#) in Manchester (UK) and at the [International Symposium on Paediatric Neuro-oncology](#) being held in Toronto next week.

CT scans in childhood: Researchers have [identified](#) a small but significant risk of brain tumours arising from cumulative doses of ionising radiation administered to children and recommend that "radiation doses from CT scans ought to be kept as low as possible and alternative procedures, which do not involve ionising radiation, should be considered if appropriate".

Therapy developments and new discoveries: e therapeutics PLC has [announced](#) a Phase 1 trial of its compound ETS 2101 in glioma patients and patients with brain metastases. One of its attractions is its ability to cross the blood brain barrier. City of Hope, which is located in California, has been

[granted](#)

a \$5,217,004 USD early translational research award by the California Institute for Regenerative Medicine (CIRM) to support the development of a T cell-based immunotherapy that re-directs a patient's own immune response against glioma stem cells. Proponents of Novocure's TTF therapy have been pleased at an unexpected theoretical physics

[paper](#)

by a scientist in Israel which is said to reinforce the underlying theory of the novel approach.

IsoRay has

[announced](#)

that doctors have "performed the world's first Cesium-131 brachytherapy seed sutured mesh

implant on a female patient suffering from a recurring meningioma tumor". Cellceutix Corporation has

[announced](#)

its belief that its compound Kevetrin has potent anticancer activity in glioma. Scientists in Singapore have

[found](#)

that GBM patients with high levels of parkin (a type of protein) survive longer, which has led them to focus on the molecular examination of tumours to identify this component. A group of researchers at the University of Hyderabad (India) have

[discovered](#)

a method to increase the shelf life and efficacy of temozolomide.

CNS PNET tumours: In an international collaboration involving the collection of 142 CNS PNET (primitive neuroectodermal) samples from 20 institutions in nine countries researchers have [identified](#) three molecular sub groups of these tumours and concluded that "LIN28 and OLIG2 are promising diagnostic and prognostic molecular markers for CNS PNET that warrant further assessment in prospective clinical trials".

Patient left in pain: The Scottish Public Services Ombudsman has [upheld](#) a complaint that a brain tumour patient was not provided with adequate care or medication when he died in pain in 2010. The patient was only administered a mild sedative and given an oxygen mask when his head swelled so badly that his ears doubled over.

Legal case about neurosurgery: Further to an earlier report in the E News a decision has now been delivered in a West Australian case about the nature of advice given to resect or not resect a young person's brain tumour some years ago. In a 176-page written decision a Perth (Western Australia) District Court judge has [stated](#) that "he was not persuaded that other neurosurgeons acting reasonably at the relevant times between 1996 and 1999 would have attempted the treatment option of resecting (a patient's brain) tumour," which is what the patient and his parents argued in their recent law case was advice that they should have been given. The case was brought against a retired neurosurgeon and a retired oncologist for their advice in 2000.

Frank Boeye: The IBTA was saddened to learn of the death on 27 May of long-term survivor Frank Boeye who led the Belgian brain tumour group Werkgroep Hersentumoren which he [established](#)

in 2005 and who was a strong and hard working advocate for brain tumour patients, their families and caregivers. Frank was diagnosed in 1997 with an AA3/GBM. The group will

continue under its new leadership which is profiled in the latest IBTA "Brain Tumour" magazine. Frank will be very much missed in the Belgian and international brain tumour community.

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Thank you for your continuing support.

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