

 <p>Dear Friend</p> <p>Proton Beam Therapy: Controversy has erupted in the UK over the relative merits of two expensive Proton Beam Therapy (PBT) machines that the Government has ordered at a cost of ♦250m (about \$402m USD) for installation in 2015 and the relative merits of less expensive Elekta and Cyberknife machines. Currently, some UK children with inoperable brain tumours travel to the USA or Switzerland for PBT treatment. In one case a family raised ♦300,000 (about \$482,000 USD) to twice send their 5 year old daughter for treatment in the USA but her tumour regrew and she is now in palliative care.</p> <p>Rindopepimut: The Celldex ACT IV study for patients with newly diagnosed EGFRvIII expressing glioblastoma is now active in 147 centres around the world, with a target of 200 centres. Centres are currently screening, or propose to screen, patients in the USA, Canada, Australia, New Zealand, Mexico, Argentina, Brazil, Colombia, India, Czech Republic, Peru, Taiwan and Thailand. The Celldex ReACT study for patients with recurrent EGFRvIII expressing glioblastoma is active in 22 centers in the USA. This trial is recruiting both Avastin na♦e and Avastin refractory patients. </p> <p>Synthetic cannabinoid: Dr Santosh Kesari in the USA is involved with a Phase I trial of multiple doses of dexamabinol (ETS2101) which is a cannabinoid derivative that causes no psychotropic effects. It is being tested on patients with either a primary or metastatic brain tumour.</p> <p>Cancer caregivers: In a paper presented at the recent ESMO conference researchers reported on a number of statistically significant impairments experienced by people who cared for cancer patients compared with non-caregivers. Dr Isabelle Gilloteau from BMS told the IBTA E-News that the analysis did not deal with brain tumour caregivers specifically. It is an area worthy of further study, particularly if it can be shown that a new therapy which results in a better quality of life for a brain tumour patient also consequentially results in less impairments suffered by their

caregivers. Some of the more forward-looking Health Technology Appraisal Agencies (HTAs) might be prepared to take that factor into consideration in their assessments. </p> <p>SurVaxM: This is an injectable vaccine which is the subject of a small Phase I

trial in the USA involving patients with a GBM or anaplastic glioma. The vaccine kills tumour cells that express Survivin, which is a protein.</p> <p>Neurosurgery simulation: In a method reminiscent of the principles of a flight simulator, Canadian neurosurgeons and other researchers have developed a system called <i>NeuroTouch</i> that uses 3-D graphics and ◆haptic tool manipulators◆ (which provide tactile feedback) to train neurosurgeons in brain operations, including the removal of a brain tumour. Prototypes have been set up in seven teaching hospitals in Canada and other simulators have been deployed worldwide.</p> <p>Pratt and Whitney Study: A study of former Pratt and Whitney workers, which was commenced in 2002 and which seeks to investigate if toxins in the workplace might have caused brain tumours, will not be reported until later this year or in early 2013. The relevant news report is available on subscription here.</p> <p>Immunotherapeutic traps: Researchers at the Barrow Neurological Institute and Arizona State University in the USA have reported that the immune system reacts differently in different brain tissues and different regions of the brain, including tumours. This finding may have implications for clinical trials involving immunotherapies.</p> <p>Appointment: Dr Maryam Fouladi has been awarded the Marjory Johnson Chair in Translational Brain Tumor Research by Cincinnati Childrens' Hospital Medical Center. Dr Fouladi wrote an article about the international DIPG registry for the current issue of the IBTA's

Brain Tumour magazine which appears on pages 122-123.

French USA collaboration: Officials from a French biotechnology company SISENE [plan to work with researchers in Georgia \(USA\) on the development of a protein called NOV c-ter, which will hopefully inhibit another protein andrenomedullin, that is associated with the growth of new blood vessels in glioblastoma tumours.](http://chronicle.augusta.com/news/health/2012-09-27/french-company-and-ghsu-partner-over-potential-treatment-brain-tumors)

Fingerprinting of tumours: UK researchers have [shown](http://medicalxpress.com/news/2012-09-fingerprinting-breakthrough-brain-tumour-diagnosis.html) that infrared and Raman spectroscopy, coupled with statistical analysis, can be used to tell the difference between normal brain tissue and the tumour types that may arise in this tissue. See also [here](http://pubs.rsc.org/en/Content/ArticleLanding/2012/AY/c2ay25544h) for the relevant journal article.

Diagnosis: Patient advocacy groups in the United Kingdom have long been concerned about late and misdiagnosis of brain tumours, particularly in children. This led to the HeadSmart program featured on pages 56-57 in the current *IBTA Brain Tumour* magazine. [New research](http://www.ncin.org.uk/publications/data_briefings/routes_to_diagnosis.aspx) by the UK National Cancer Intelligence Network of the diagnosis of 739,667 tumours in English patients between 2006-2008 reveals that 58% of CNS tumours were diagnosed in an emergency presentation. This percentage compared with 38% of lung cancers diagnosed in emergency presentations but pancreatic cancer diagnosis was also high at 47%. The average for all cancers was 23%. A recent Canadian

[study](http://www.esmo.org/fileadmin/media/pdf/2012/press/ESMO-Press-Release-Noteworthy-Studies-at-the-ESMO-2012-Congress.pdf) has also found unacceptable delays in diagnosis and treatment of adolescent and young adult brain tumour patients. The English finding for CNS tumours tends to reinforce the appropriateness of brain tumour-specific educational training among emergency staff in hospitals.

Meningiomas: Meningiomas have not received as much clinical investigation as, say, glioblastoma, and therefore the Principal Investigator for the RTOG 0539 trial (a Phase II trial of observation for low-risk meningiomas and of radiotherapy for intermediate and high-risk meningiomas) was pleased to report in the final newsletter for this trial that accrual had now

been completed. Meanwhile, Dr James Fahner (founder of the Cancer and Hematology program at Helen DeVos Children's Hospital in the USA) has talked [publicly](http://www.mlive.com/news/grand-rapids/index.ssf/2012/09/how_leader_of_devos_childrens.html) of his diagnosis with a meningioma and his new experience as a patient, describing himself as **the world's worst patient**.

ClinicalTrials.gov enhancements: The designers of the ClinicalTrials.gov website are obviously [conscious](http://www.nlm.nih.gov/pubs/techbull/ja12/ja12_clinicaltrials.html) of the fact that their resource is used by patients and the public searching for relevant clinical trials and not just by clinicians and researchers. The **About Clinical Studies** section now contains several enhanced features, including a glossary of common words used on the website.

Morphine for paediatric patients: New dosage recommendations for morphine for paediatric patients have been issued by the World Health Organisation which are described as "a more cautious approach". They have been noted in the [October issue](http://www.who.int/medicines/areas/quality_safety/ACNewsletter_13_October12_1.pdf) of the *WHO Access and Control Newsletter* in which an article has been published as an Annex.

Patient input to drug development and evaluation: In what could prove to be a significant opportunity for patient input into drug development the FDA has [scheduled](http://www.gpo.gov/fdsys/pkg/FR-2012-09-24/pdf/2012-23454.pdf) two public meetings to discuss process questions for patient-focussed drug development. The first meeting will be held on 25 October and will discuss a suggested list of 20 disease areas for focus in a forthcoming series of 20 public meetings. The cancer subjects listed are melanoma, lung cancer, cancer and young patients, cancer treatment in pregnancy, cancer and sexual dysfunction, and cancer and depression. Readers in the USA might care to consider if it would be useful to encourage the FDA to include brain tumours within this list. Patient stakeholders will be invited to another series of meetings, on as yet unspecified dates, to discuss patient-focussed drug development more generally.

Cancer and movies: In a [study](http://www.eurekalert.org/pub_releases/2012-09/esfm-cit091812.php) of 82 movies that centre on a person with cancer, presented to the recent ESMO meeting in Vienna, Italian researchers found that there was often a disconnection between the scenario portrayed in the movies and what is happening in the treatment clinic. They also found that relatively rare leukaemia, lymphomas and brain tumours predominate among the movies. Death from cancer occurred in 63% of all movies. Dr Luciano De Fiore told IBTA co-director Kathy

Oliver that 14 of the 82 movies they studied dealt with a patient with a brain tumour.

ESMO play: Satire is a difficult art form. In Vienna recently officials of the European Society of Medical Oncology (ESMO) arranged for a short play to be performed during its conference which contained a grotesque parody of three types of patient: one who, as if in a trance, continuously murmured New-Age type chants throughout the consultation (the patient with a complementary and alternative medicine approach); one patient (presumably the aggressive type) who was accompanied by a medico-legal lawyer who bullishly insisted on taping the consultation; and one patient who repeatedly harangued the doctor with her scientific knowledge. All three were diagnosed with cancer. The doctor (a research professor at a well-known, but thinly veiled, London cancer hospital) had contravened bureaucratic EU research rules (the play is set in the year 2084) and, in a scene reminiscent of George Orwell's 1984, had been sent to Room 101 for his miscreant activity. His punishment in Room 101? To have to see the three patients which, judging by the uproarious laughter and hearty applause from the several hundred health professionals in the audience, struck a chord. It was a severe embarrassment to the patient advocates who were present and not something that one would expect to find at similar conferences elsewhere.

Deadline: The early registration [deadline](http://www.soc-neuro-onc.org/en/cev/76) for the SNO annual scientific meeting and education day in Washington DC in November is 15 October.

Thank you for your continuing support.

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