

Dear All

The cost of premature cancer-related mortality: In an important [study](http://www.biomedcentral.com/1471-2407/14/224) which looked at the cost of premature cancer-related mortality in Ireland in 2009 and which was published as recently as 26 March 2014, researchers have confirmed that the cost to the community of the deaths of people with brain and CNS tumours is disproportionate to the incidence and ranking of the disease.

They measured the economic burden by *years of potential productive life lost* (YPLL). The premature mortality cost for brain and CNS tumours ranked 3rd at **€42.4 million** (about \$58m USD) which contrasted with their 7th ranking place in terms of number of cancer deaths in Ireland. The individual cost per each brain and CNS death was **€421,200** (about \$580,000 USD) for males and **€202,542** for females (about \$279,000 USD), which represented the second most expensive of all cancer deaths in terms of cost per death. These figures are influenced by the low survival and relatively low age at diagnosis of people with brain and CNS tumours.

New Chair for the IBTA. Following the recent IBTA [announcement](http://www.theibta.org/Announcement.pdf) of Chair and Co-Director Denis Strangman's retirement from the International Brain Tumour Alliance, IBTA Co-Director Kathy Oliver will become Chair of the organisation effective as of 3rd June. Kathy and Denis will attend the annual scientific conference of the American Society of Clinical Oncology (ASCO) where the IBTA will have a slot in the combined patient advocacy booth (#3005).

Brain Tumour magazine: The IBTA intends to print in early May 12,000 copies of the annual *Brain Tumour* magazine for free distribution to its contacts in 109 countries and to participants at relevant scientific and patient conferences. Readers of this E-News who have not received a past copy of the magazine in the mail should notify their land address to ibtainfo@gmail.com before 1 May in order to be included in the mail-out.

Heavy cost of unnecessary headache-related brain scans: A [study](https://archinte.jamanetwork.com/article.aspx?articleid=1835347) in the USA has identified a cost of \$1 billion for brain scans for headache patients. Neurologist Dr Brian Callaghan, who led the study said **There's solid research showing that the number of times you find serious issues on these scans in headache patients is about the same for a randomly chosen group of non-headache patients ... And a lot of the things we find on such scans aren't necessarily something we will do something about.**

Comment This finding is relevant to the question of (1) reducing misdiagnoses and delayed diagnoses of brain tumours; and (2) the usefulness or otherwise of population-based scanning for brain tumours. In some countries there appear to be too many occasions of missed diagnosis because of a failure to refer for a scan. On the other hand we are aware that random scanning would have to be repeated on individuals at least every six months to identify a brain tumour which, as we know, can appear with little or no warning.

~~Comment~~

eMEET on-line resource: A new online, interactive training programme designed to help patient advocates better understand medicines development and health technology assessment has been launched. ~~See [here](#) to access the resource~~

Developed by Eli Lilly and Company in collaboration with internationally renowned experts in the fields of patient involvement and health technology assessment (HTA), the eMEET (Medicine Evaluation Educational Training) online resource is a unique tool designed to help patient advocates navigate the complex world of medicines development, evaluation and assessment. eMEET is endorsed by Health Technology Assessment International (HTAi), the global scientific and professional society for those who produce, use, or encounter HTA. See [here](#) to access the resource

Your chance to help influence brain tumour research: James Lind Alliance (JLA) Priority Setting Partnerships in the UK give those most directly affected by a disease the opportunity to influence the direction of future research. The Neuro-Oncology JLA Priority Setting Partnership invites all patients, friends, caregivers, relatives and health professionals to submit the topics they think need to be researched to improve outcomes for people with brain and spinal cord tumours. The research questions submitted will be prioritised by a panel of patients, clinicians and charity representatives. The final **Top 10** topics will be promoted to research organisations and funding bodies, such as the *National Institute of Health Research UK* and the *European Organisation for Research and Treatment of Cancer*. Visit www.neuro-oncology.org.uk for more information and to take part. The survey closes on 30 April 2014.

Book by Mr Henry Marsh (UK): Neurosurgeon Henry Marsh, who specialises in brain tumours, has written a book about his career. There is a review available [here](http://www.telegraph.co.uk/culture/books/bookreviews/10680985/Do-No-Harm-Stories-of-Life-Death-and-Brain-Surgery-by-Henry-Marsh-review.html). Mr Marsh carries out important pro bono work in the Ukraine where he has generously assisted in one of the hospitals.

Meetings and deadlines: The [deadline](http://www.bnos.org.uk/conference.html) for the early-bird registration for the Annual British Neuro-oncology Society (BNOS) Conference to be held on 9-11 July is 30 April 2014. The [deadline](http://www.asno2014.org/abstracts-32.html) for the 11th meeting of the Asian Society for Neuro-Oncology (ASNO) to be held at Istanbul during 11-14 September, is 16 May. Abstract submissions for the World Cancer Congress being held in Melbourne, Australia, during 3-6 December, are now [open](http://www.worldcancercongress.org/programme/call-abstracts-now-open)

and close on 30 May.

Abstract submissions for the 19th Annual Scientific Meeting and Education Day of the Society for Neuro-Oncology, to be held in Miami during 13-16 November, close on 9 June.

Radiofrequency guidelines: A panel of the Royal Society of Canada has advised against the introduction of any additional precautionary measures for Health Canada's Safety Code 6 which sets out limits to exposure to radiofrequency fields aimed at protecting the health of workers and the general public, although the panel did advise that Health Canada should pursue research on the subject. A news item reporting this decision mentions an international study MOBI-KIDS which is assessing radiofrequency fields and brain tumours in the child and young adult populations.

UK stereotactic radiosurgery: UK newspapers have referred to a letter of complaint to NHS England written by neurosurgeon Matthias Radatz and signed by thirteen specialists, which includes every regional representative of the Radiosurgery Clinical Review Group in England. The letter is said to refer to a lack of trained staff, restrictions on the use of advanced radiotherapy, and threats to close 18 specialist (radiosurgery) centres.

Watson to sequence DNA: The computer company IBM will use its Watson cloud computing system, in conjunction with the New York Genome Center, to sequence the DNA of twenty brain tumour patients in order to identify the best ways to treat them. It has been claimed that the system can do in seconds that which might take people years to accomplish.

Doctor Stanislaw Burzynski: The US Food and Drug Administration (FDA) has agreed to allow the parents of eight children to have access to the antineoplastins produced by controversial oncologist Dr Stanislaw Burzynski but only if (according to the linked newspaper report above) they can find a qualified, independent physician to administer the drug. Beyond infusing the drug and overseeing their care, the doctor would have to formally apply for expanded access to an "investigational new drug," as well as get approval from an institutional review board, an independent panel that reviews safety and ethical issues involved in clinical trials.

Company developments

MagForce and MF 1001: The German company MagForce has announced the enrolment of the first patient in the MF 1001 clinical trial assessing its NanoTherm therapy as monotherapy and in combination with radiotherapy compared to radiotherapy alone in GBM patients. The event occurred at the University Hospital Muenster

under the leadership of Professor Dr Walter Stummer. The therapy involves the injection of superparamagnetized iron oxide nanoparticles into the tumor and their heating in the alternating magnetic field of the NanoActivator.

In a [letter](http://www.magforce.de/fileadmin/magforce/5_presse/Shareholder_Letter/MagForce_Shareholder_Letter_March_31__2014.pdf) to shareholders the company confirmed its proposed expansion in EU 28 countries, including Germany, and stated ... we continue preparing our registration path for the USA. In December, we filed a presubmission with the FDA and expect our dialog with the agency will be most helpful as to defining the regulatory path for NanoTherm therapy ...

PBTF and Siemens: In a very interesting [innovation](http://www.curethekids.org/about-us/news-room/pbtf-news/2014/news.html) worthy of adaptation elsewhere the US-based Pediatric Brain Tumor Foundation (PBTF) has partnered with Siemens Hearing Instruments Inc to distribute top-of-the-line hearing aids and audiology services to patients with brain tumors and other forms of childhood cancer. Hearing loss can result from platinum-based chemotherapy and radiation therapy.

G-202: A small Phase II [trial](http://www.genspera.com/press/140318_FIRST_PATIENT_ENROLLED_IN_GENSPERA_G-202_PHASE_II_GLIOMASTOMA_TRIAL.pdf) of GenSpera's G-202 involving 34 patients with recurrent glioblastoma has commenced at UC San Diego Moores Cancer Center. The drug is activated by the enzyme PSMA.

Brain-derived exosomes: Aethlon Medical Inc [announced](http://aethlonmedical.investorroom.com/2014-03-19-Aethlon-Medical-and-Exosome-Sciences-Expand-Brain-Research-Discoveries-to-Include-Isolation-of-Glioblastoma-Biomarker-and-Therapeutic-Target) that it had isolated brain-derived exosomes released into the bloodstream from glioblastoma tumours, thereby holding promise as both a disease biomarker and therapeutic target.

I-124-CLR1404: Celectar Biosciences (formerly Novelos Therapeutics) has [announced](http://celectar.com/2014/celectar-announces-initiation-of-phase-ii-imaging-trial-with-i-124-clr1404-in-patients-with-newly-diagnosed-or-recurrent-glioblastoma/) the enrolment of its first patient in a Phase II trial of its new PET imaging technology. I-124-CLR1404 in glioblastoma.

Regeneus: Regeneus believes that a recent academic [paper](http://cancerimmunolres.aacrjournals.org/content/early/2014/02/21/2326-6066.CIR-13-0157.abstract) showing a remission rate of 30-60% in a rat glioma model using its Kvac cancer vaccine shows its efficacy and safety.

Tocagen: Tocagen [announced](http://www.tocagen.com/press/tocagen-doses-first-patient-intravenously-in-clinical-trial-of-selective-cancer-therapy-toca-511-toca-fc/)

'Arial','sans-serif';">announced that the first patient has been dosed in its clinical trial investigating the intravenous administration of selective cancer therapy Toca 511 and Toca FC, in patients with recurrent high grade glioma (HGG) including glioblastoma multiforme.</p> <p>Vacquinol-1: Swedish researchers using in vivo models have identified the potential for vacuolization (whereby the cell membranes collapse) in attacking glioblastoma cells.</p> <p style="line-height: 16.2pt; margin: 0cm 0cm 7.5pt; background: none repeat scroll 0% 50% white;">Focused ultrasound: In March the US-based Focused Ultrasound Foundation hailed the use for the first time of focused ultrasound ♦using InSightec♦s ExAblate Neuro system♦ on a patient with recurrent glioma. Part of the person♦s tumour was thermally ablated through the intact skull.</p> <p>Prognosis: The widow of the late Senator Edward Kennedy, who died from a brain tumour, delivered a sharp rebuke to those who would issue a pessimistic prognosis. In a commentary published in a local newspaper which has just come to light she wrote: ♦When my husband was first diagnosed with cancer, he was told that he had only two to four months to live, that he'd never go back to the U.S. Senate, that he should get his affairs in order, kiss his wife, love his family and get ready to die.</p> <p> </p> <p style="margin: 0cm 0cm 7.5pt; background: none repeat scroll 0% 50% white;">♦But that prognosis was wrong. Teddy lived 15 more productive months. During that time, he cast a key vote in the Senate that protected payments to doctors under Medicare; made a speech at the Democratic Convention; saw the candidate he supported elected president of the United States and even attended his inauguration; received an honorary degree; chaired confirmation hearings in the Senate; worked on the reform of health care; threw out the first pitch on opening day for the Red Sox; introduced the president when he signed the bipartisan Edward M. Kennedy Serve America Act; sailed his boat; and finished his memoir "True Compass," while also getting his affairs in order, kissing his wife, loving his family and preparing for the end of life.</p> <p style="margin: 0cm 0cm 7.5pt; background: none repeat scroll 0% 50% white;">♦Because that first dire prediction of life expectancy was wrong, I have 15 months of cherished memories ♦ memories of family dinners and songfests with our children and grandchildren; memories of laughter and, yes, tears; memories of life that neither I nor my husband would have traded for anything in the world.</p> <p style="margin: 0cm 0cm 7.5pt; background: none repeat scroll 0% 50% white;"><span style="font-family: 'Arial','sans-serif'; color: #222222; font-size:

10pt;">◆When the end finally did come ◆ natural death with dignity ◆ my husband was home, attended by his doctor, surrounded by family and our priest.◆

Overview of GBM therapies in development: A researcher associated with a drug monitoring company, which is following 47 pre-registration drugs for glioblastoma, has given an interesting insight into the status of these therapies which is freely available [here](http://www.pmlive.com/pharma_news/glioblastomas_-_a_personalised_future_557654).

Bevacizumab and children: Bevacizumab (Avastin) has been [added](http://www.pharmatimes.com/Article/14-03-24/Three_more_drugs_make_England_s_Cancer_Drugs_Fund.aspx) to England's Cancer Drugs Fund to treat low grade glioma in children to try and delay the need for radiotherapy until the patient is older and less likely to develop side effects to radiotherapy.

Journalist's guide to covering cancer: The European Society of Oncology's (ESO) media team have published a *Journalist's Guide to Making Sense of Cancer*, which is available [here](http://www.cancerworld.org/Media/Media_Guide.html). It is also a useful guide for patient advocacy groups.

Thank you for all your continuing support.

Denis Strangman (Chair and Co-Director) International Brain Tumour Alliance IBTA

www.theibta.org/

chair@theibta.org

[Kathy Oliver](mailto:kathy@theibta.org)

style="font-family: 'Arial','sans-serif'; color: black; font-size: 12pt;"> (Co-Director)
 PO Box 244, Tadworth, Surrey
 KT20 5WQ, United Kingdom
 Tel:+ (44) + (0) + 1737 813872
 Fax: + (44) + (0) +1737 812712
 Mob: + (44) + (0) + 777 571 2569
