

Hormone replacement therapy (HRT) and meningiomas: A Danish [study](http://emailcontrol.com.au/link.php?M=15975284&N=37867&L=52978&F=H) of 924 women who had a meningioma has led to a [claim](http://emailcontrol.com.au/link.php?M=15975284&N=37867&L=52981&F=H) that women on HRT have a 30 percent greater risk of getting a meningioma brain tumour but the findings have been [dismissed](http://emailcontrol.com.au/link.php?M=15975284&N=37867&L=52989&F=H) by experts in women's health. One consultant endocrinologist said that the risk might only represent one per 100,000 women per year and was an absolutely trivial risk and of no clinical or biological importance. Another expert said that with women who experience early menopause the benefits of HRT are likely to substantially outweigh the long-term risks without HRT, which included osteoporosis and cardiovascular diseases.

Piloctytic astrocytomas: German researchers working within the PedBrain consortium have now [published](http://emailcontrol.com.au/link.php?M=15975284&N=37867&L=52976&F=H) the results of the first 96 genome analyses of pilocytic astrocytomas. They have found that overactive MAPK (mitogen-activated protein kinase) signals are necessary for a pilocytic astrocytoma to develop. They also found that the genomes of pilocytic astrocytomas contain far fewer mutations than in medulloblastomas, for example, and that cerebellar astrocytomas are genetically even more homogeneous than other cases of the disease. Professor Stefan Pfister, who leads the research, said that targeted agents for all pilocytic astrocytomas are potentially available to block an overactive MAPK signalling cascade.

Comment: Some cancer registries do not even bother to record the location of a patient's brain tumour. In this instance the identification of cerebellar astrocytomas may have significance for long-term research. Patient advocates should press for more detailed information to be recorded about brain tumours in national cancer and brain tumour specific registries.

Patient misdiagnosed with depression: In a succession of [tragic errors](http://emailcontrol.com.au/link.php?M=15975284&N=37867&L=52979&F=H) a 34-year old man died from his brain tumour in Essex (UK) after being misdiagnosed for four weeks in 2011 by three senior doctors who treated him for depression. It was only when he lost the use of his right hand that his tumour was discovered. He initially presented with speech problems and was prescribed 20 mgs of citalopram, sleeping pills and referred for counselling. Later, staff at a hospital mental health unit could not understand him because of his speech problem and he left. After a year-long examination by the General Medical Council (GMC) two of the doctors were told to reflect upon the GMC's expert's findings and their assessments of the patient were found to fall seriously below that of a reasonably competent GP. The third doctor was found to have failed to consider other causes of the patient's initial speech problems but no further action was taken. The patient's grieving father [wants](http://emailcontrol.com.au/link.php?M=15975284&N=37867&L=52983&F=H) the GPs suspended. The medical practice, in turn, has

[given](http://emailcontrol.com.au/link.php?M=15975284&N=37867&L=52980&F=H) the father a week to find another practice for his own medical needs, saying he is no longer welcome there.

Comment: Misdiagnoses of paediatric brain tumour patients in the UK have resulted in the very successful

[HeadSmart program](http://emailcontrol.com.au/link.php?M=15975284&N=37867&L=37031&F=H) for children and young people and its

[spread to Europe](http://emailcontrol.com.au/link.php?M=15975284&N=37867&L=52990&F=H). Special attention might also be needed to reverse misdiagnosis of adult brain tumours.

Long term effects: Parents of Canadian children treated for their cancer when young have

[formed](http://emailcontrol.com.au/link.php?M=15975284&N=37867&L=52964&F=H) a Pediatric Cancers Survivorship Society of B.C. (British Columbia) to advocate for better treatment for their now adult children who suffer from complex health problems. Some of these children were given heavy doses of radiation or chemotherapy when young but treatments have now changed following greater recognition of possible long-term effects. A doctor who sought government funding to identify past paediatric patients who should be warned about possible late effects has had his request rejected.

Surveys: Cancer Research UK is undertaking an international on-line study of key issues in cancer surgery services. The twenty-minute

[on-line survey](http://emailcontrol.com.au/link.php?M=15975284&N=37867&L=52974&F=H) will target professionals and policymakers in six countries: the UK, Australia, Canada, Denmark, Norway and Sweden and has a deadline of 31 July. UK neurosurgeon Dr Colin Watts has circulated information about the survey through the British Neuro Oncology Society. They are hoping to identify cancer surgery trends, performance and challenges and to identify examples of best practice.

Another survey of interest to brain tumour professionals is one initiated by the SIOP Europe DIPG Network. The survey, which is closing soon, seeks clinical information from professionals who treat DIPG patients about the use of steroids in the DIPG context and palliative care in DIPG. There are separate surveys for professionals within Europe and outside Europe:

Steroids Outside Europe -

<http://www.t hesistools.com/web/?id=358233> Password = DIPGsteroids

Palliative care Outside Europe -

<http://www.t hesistools.com/web/?id=358234> Password = DIPGPcare

Steroids - Europe

<http://www.t hesistools.com/web/?id=356959> Password = DIPGsteroids

Palliative care Europe -

<http://www.t hesistools.com/web/?id=357215> Password = DIPGPcare

The role of humour: US researchers who undertook a study of the reactions of College students have

[concluded](http://emailcontrol.com.au/link.php?M=15975284&N=37867&L=52975&F=H) that humor helps the individual to tolerate latent anxiety that may otherwise be

destabilizing.

As if to prove the researchers' theory correct a 44 year-old Scottish journalist launched a blog [Hole in The Head](http://emailcontrol.com.au/link.php?M=15975284&N=37867&L=52972&F=H) in 2011 where he chronicled with humour and wit his journey with a brain tumour. He passed away in June 2013. In his last entry on 13 April he wrote: "Cancer death can be so cruel and undignified. At least with glioblastoma it seems that there is no pain, no suffocation, no pneumonia, no dwindling out of personality into dementia. Eventually the tumour fatigue takes hold and you simply sleep it away. But until then, I fully intend to enjoy myself as much as I can. I will remain me until the end, and I will not waste that time on self-pity and fear. And I will fight with every resource at my disposal. I have a strong mind, and I'm not planning on going anywhere gently." He had commenced that day's blog with a sarcastic comment about plastic shopping bags: "I'm keeping out of supermarkets. Two quid for a bag for life? If I'm going to spend that kind of money on a plastic carrier, I expect it to last past the autumn."

Passing of Dr Greg Foltz: The IBTA was told at the recent ASCO meeting in Chicago by two friends of distinguished neurologist Dr Greg Foltz of Swedish Neuroscience (USA) of his deteriorating condition due to pancreatic cancer. Dr Foltz [died](http://emailcontrol.com.au/link.php?M=15975284&N=37867&L=52985&F=H) on 27 June a few weeks after turning 50. He had founded and directed the Ben & Catherine Ivy Center for Advanced Brain Tumor Treatment at Swedish Medical Center. There is a supportive video news tribute to Dr Foltz [here](http://emailcontrol.com.au/link.php?M=15975284&N=37867&L=52971&F=H). We had planned to interview Dr Foltz for the 2014 *Brain Tumour* magazine and conveyed some questions through his friends, should he wish to say something on the record but unfortunately this was not to be the case. We do know, however, that his friends had it in mind to try and create a repository for his genomic research and Marty Tenenbaum has supplied the IBTA with this information:

"Marty Tenenbaum, Chairman of Cancer Commons, and Tony Blau M.D., who heads the University of Washington's new Center for Cancer Innovation were close colleagues of Dr. Foltz. Together the three founded Partners in Personal Oncology, a non-profit organization for precision oncology: using the latest scientific tools and knowledge to match each patient to the best available drugs and trials, based on the molecular subtype of their tumor, and to learn as much as possible from their clinical response.

"As one of his last acts, Greg generously agreed to donate his personal database of clinical and molecular data from hundreds of GBM patients to further this mission. We hope this will inspire his colleagues, as well as individual GBM patients, to contribute their data to create a continuously updated knowledge base linking molecular subtypes of GBM to treatments and trials. Please consider contributing your data to this knowledge base, which will serve as a lasting legacy to Greg's work, and an invaluable resource to GBM researchers, clinicians and patients. To learn more, email us at GBM@cancercommons.org or Marty Tenenbaum (jmt@cancercommons.org) and Tony Blau (tblau@u.washington.edu)

NCI data set: A [data set](http://emailcontrol.com.au/link.php?M=15975284&N=37867&L=52991&F=H) of cancer-specific genetic variations made publicly available by scientists at the US

National Cancer Institute (NCI) to cancer researchers, includes data from brain tumour tissue and will enable researchers to identify possible new genomic defect targets and to overcome acquired resistance.

Meetings: The ABTA's Patient and Family Conference will be held in Chicago during 26-27 July.

Company developments: The German-based company Apogenix GmbH has obtained patents in Europe and Canada to cover its lead product Apocept (APG 101) which is being investigated for treating glioblastomas.

German firms Immatics and BioNTech will lead a consortium of 14 organisations, including those from Spain, the UK, Switzerland, Denmark, the Netherlands, and the USA, in the development of biomarker-guided actively personalised vaccines to treat glioblastoma. The project has also been supported by a €6m grant from the European Union.

The Belgian-based firm Activartis has received orphan drug status from the US Food and Drug Administration (FDA) for use of its investigational cancer immunotherapy AVO113 in treating malignant glioma.

Ophthalmologists and brain tumours: There have been many occasions where a person's brain tumour has been discovered during an eye examination, either as part of a regular check-up or during an examination prompted by vision or other problems. In Australia the Australian Society of Ophthalmologists and the Royal Australian and New Zealand College of Ophthalmologists have launched legal action against a health regulator to prevent optometrists being able to diagnose and treat glaucoma. One of their spokespeople said "Glaucoma can be notoriously difficult to diagnose and can be confused with brain tumours and neurological diseases."

This didn't stop a UK optometrist recently from immediately referring a woman to hospital after she complained of a "pulling" sensation in her eye and the optometrist identified that sight in her left eye had deteriorated significantly since her last eye examination in 2009. At the hospital doctors diagnosed her with a pituitary brain tumour.

Meanwhile, US woman Meg Brooker will run in the Missoula half-marathon this Sunday just one day before completing her radiation therapy for an oligodendroglioma brain tumour and three and a half months after her neurosurgery. Her radiation oncologist, neurologist and medical oncologist will also be running in the half-marathon. Ms Brooker's brain tumour was discovered in April after she experienced double vision and saw an eye doctor who said she had a hemorrhage behind her left eye and an inflamed optic nerve behind her right eye and recommended an urgent MRI.

Great Dane precedent: A Colorado University

(US) researcher who used his knowledge of immunotherapy to [treat](http://emailcontrol.com.au/link.php?M=15975284&N=37867&L=52977&F=H) his pet Great Dane dog is now proposing to initiate human trials utilising the same methods against glioblastoma. The 12 year old dog, called **Star**, developed advanced bronchoalveolar adenocarcinoma (lung cancer) and the doctor [treated](http://emailcontrol.com.au/link.php?M=15975284&N=37867&L=52987&F=H) the dog with a 10-gram sample of its tumor enriched into an injectable vaccine that contained a high concentration of heat shock proteins in **chaperone-rich cell lysate** (CRCL). The dog survived for an unexpected extra 44 weeks.

Palliative care: The UK Liverpool Care Pathway for dying patients will be abolished after an independent review by Lady Neuberger, who was appointed by the UK Government following reports that under the scheme dying patients had been drugged and deprived of fluids. Lady Neuberger was [quoted](http://emailcontrol.com.au/link.php?M=15975284&N=37867&L=52973&F=H) as saying "Caring for the dying must never again be practised as a tickbox exercise and each patient must be cared for according to their individual needs and preferences, with those of their relatives or carers being considered too". There were references to poor training and sometimes a lack of compassion on the part of nursing staff and junior doctors who were expected to make life and death decisions beyond their competence.

Comment: This outcome will have implications in countries such as Canada and Australia which had been following the UK Pathway model with interest and using it as a guide for their own end of life pathway plans.

Thank you for all your continuing support.

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