

<p><br /> If you are having difficulty in reading this version please go to the Web version <a title="http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43353&F=H" href="http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43353&F=H">here</a>.<br /> <br /> <b>UK patient satisfaction survey:</b> In a disturbing official report of the results of a patient satisfaction survey undertaken during 2011/2012 among 71,793 cancer patients in the UK it has been found that "... some types of cancer, such as brain and central nervous system and sarcoma, have scores on particular questions which are 20-30 percentage points worse than those given by patients in the best rated cancer groups." The 168 page report can be accessed <a title="http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43351&F=H" href="http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43351&F=H">here</a>. Brain tumour organisations in the UK (including the IBTA) have formed a <a title="http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43374&F=H" href="http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43374&F=H">Consortium</a> to work together to improve brain tumour policy and services.<br /> <br /> <b>ImmunoCellular Therapeutics</b>: Dr Manish Singh, the President and CEO of ImmunoCellular Therapeutics has <a title="http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43367&F=H" href="http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43367&F=H">stepped down</a> and will be replaced by the Chair and founder Dr John S Yu on an interim basis. The company has been developing its vaccine therapy ICT-107 for glioblastoma. There is some commentary on the personnel changes <a title="http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43376&F=H" href="http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43376&F=H">here</a>. Meanwhile, on 3 August promising results of the Phase 1 trial at Cedars-Sinai were published in the journal <i>Cancer Immunology, Immunotherapy</i>, which is freely available <a title="http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43354&F=H" href="http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43354&F=H">here</a>.<br /> <br /> <b>Avastin:</b> On 10 August Roche <a title="http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43359&F=H" href="http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43359&F=H">announced</a> that "... the phase III AVAglio study of Avastin plus radiation and temozolomide chemotherapy in people with newly diagnosed glioblastoma met its co-primary endpoint of a significant improvement in progression-free survival (PFS)." They also stated that "Data for final overall survival (OS), the other co-primary endpoint, are expected in 2013 ... No new safety findings were observed in the AVAglio study and adverse events were consistent with those seen in previous trials of Avastin across tumour types for approved indications. Full data from the AVAglio study will be submitted for presentation at an upcoming medical meeting." There has been speculation that the meeting could be the upcoming Society of Neuro Oncology <a title="http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43356&F=H" href="http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43356&F=H">conference</a> to be held in Washington during 15-18 November.<br /> <br /> <b>ESMO award:</b> Professor Jean-Yves Blay, a former president of the EORTC (European Organisation for the Research and Treatment of Cancer) who has been very active in the European rare cancer movement, will receive an <a title="http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43370&F=H" href="http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43370&F=H">award</a>

at the Opening Ceremony of the ESMO (European Society for Medical Oncology) conference in Vienna during 28 September - 2 October. EORTC itself will also receive an award. Readers may recall that the 2012 IBTA magazine carried an article by the EORTC's President-elect Dr Roger Stupp to mark its 50th anniversary this year. The IBTA plans to exhibit at both the <http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43371&F=H> patient seminar section of the ESMO conference and the preceding <http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43373&F=H> conference of the European Association of Neuro-Oncology (EANO) to be held at Marseille during 6-9 September. **Spanish research:** In a six-minute eCancerTV <http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43380&F=H> interview following the July EACR (European Association for Research of Cancer) meeting Dr Joan Seoane of Vall d'Hebron Institute of Oncology, Spain, explained how researchers are isolating Glioma Initiating Cells (GICs) from culturing a patient's glioblastoma tumour obtained during neurosurgery and implanting them in mice. The process enables researchers to observe the development of the mouse tumour and to suggest experimental therapies which might be relevant to the particular patient. Dr Seoane chaired a pre-EACR meeting on brain tumour research supported by the Seve Ballesteros Foundation and which featured several international speakers. The program and a small abstract book can be downloaded from <http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43383&F=H> here. **The consequences of delayed radiotherapy for newly diagnosed GBM:** Contrary to previous research, a new <http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43355&F=H> study published at the end of July by a team at the University of Barcelona (Valdúvico et al) has concluded that survival is significantly reduced in glioblastoma patients if radiotherapy is not initiated within six weeks following complete resection of the tumour. On the other hand, a study based on patients at 18 centres in France who were involved in the EORTC-NCIC concomitant trial and <http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43365&F=H> published in *Neuro-oncology* in August concluded that "In this large series treated during the EORTC-NCIC protocol period, waiting time until radiotherapy did not seem to affect patient outcome." **Imetelstat:** There is an interesting speculative article which is linked to <http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43362&F=H> here about the likely future course for Geron Corp's Imetelstat and its possible relevance to brain metastases from lung and breast cancers. The article suggests that it is not yet clear which cancers the company may decide to target. **European Inquiries:** The European Commission has initiated inquiries into the <http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43382&F=H> potential health effects of electromagnetic fields (EMF) and the safety of medical devices containing nanomaterials. In the latter it specifically <http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43382&F=H>

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the need for a clarification of the possible relevance of the inquiry to Magforce's [title="http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43368&F=H"](http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43368&F=H)  
[href="http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43368&F=H">NanoTherm](http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43368&F=H)  
therapy</a> for brain tumours which is now available in Germany. Meanwhile, researchers at the UCL Cancer Institute in the UK are [title="http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43352&F=H"](http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43352&F=H)  
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ng</a> with Ferucarbotran, which is a SPION (superparamagnetic iron oxide particle) to be administered to patients with glioblastoma who will then have their tumour subjected to MACH (magnetic alternating current hyperthermia) technology, which will heat the particles in the tumour and hopefully generate a toxic effect.<br /> <br /> <b>DNATrix Inc:</b> DNATrix Inc, which is based in Houston, [title="http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43379&F=H"](http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43379&F=H)  
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preparing</a> a Phase 2 study of its adenovirus Delta-24-RGD, to commence early in 2013, for trial against high grade gliomas. The Phase 1 study was conducted at the MD Anderson Cancer Center.<br /> <br /> <b>Cancer stem cells</b>: Articles in [title="http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43366&F=H"](http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43366&F=H)  
[href="http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43366&F=H"><i>Nature</i></a> and \[title="http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43357&F=H"\]\(http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43357&F=H\)  
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</i></a> in early August, based on work on mice by researchers in the USA and Europe, \[title="http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43363&F=H"\]\(http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43363&F=H\)  
\[href="http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43363&F=H">suggest</a>\]\(http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43363&F=H\)  
> that cancer stem cells can be found in brain tumours and early forms of skin and colon cancer. If this proves correct then it opens up a new target for future therapies.<br /> <br /> <b>Webinar and Podcasts:</b> The American Brain Tumor Association has \[title="http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43350&F=H"\]\(http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43350&F=H\)  
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</a> that it will provide a webinar by Dr Timothy Cloughesy on "Understanding Brain Tumours" on 27 September which will be recorded and posted on its website later. The Cancer Council in Queensland \(Australia\) also plans to upload as a podcast two presentations by US visitor Dr Susan M Chang at a patients' and caregivers' Forum organised by \[title="http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43349&F=H"\]\(http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43349&F=H\)  
\[href="http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43349&F=H">Brain\]\(http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43349&F=H\)  
Tumour Alliance Australia</a> on 11 August.<br /> <br /> <b>PNET tumours:</b> In a study published in \[title="http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43364&F=H"\]\(http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43364&F=H\)  
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\*Lancet Oncology</i></a> of CNS primitive neuro-ectodermal tumours \(PNETs\) led by Principal Investigator Dr Annie Huang from Toronto's SickKids Hospital researchers discovered three molecular subgroups of these fairly rare paediatric brain tumours. The \[title="http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43369&F=H"\]\(http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43369&F=H\)\*](http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43366&F=H)

<http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43369&F=H>>hope</a> is that the findings may lead to more specific treatment approaches. There is an interview with Dr Huang at page 38 of the recent issue of the IBTA's *Brain Tumour* magazine. Readers can obtain a free copy of the magazine by filling in the on-line form located <http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=35695&F=H> here</a>.

**Impact on patients and caregivers:** The June issue of the <http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43372&F=H>><i>European Journal of Oncology Nursing</i></a> contains a systematic review by Belgium-based <mailto:wendy.sterckx@uzleuven.be> Wendy Sterckx et al of 16 qualitative studies relevant to the impact of a high-grade glioma on patients and caregivers. Not surprisingly there is an identification of dissatisfaction about received support or lack of adequate support by both patients and caregivers.

**Survival:** In a major report in the <http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43377&F=H>><i>International Journal of Cancer</i></a> on "Survival of European patients with central nervous system tumours", estimates of population-based 5-year relative survival (1988-2002) were 85% for benign and 19.9% for malignant tumours. While this led the authors to suggest that the absence of improved survival for malignant tumours indicated "no useful advances in treatment" the implementation of the Stupp regimen as standard therapy is more likely to show up in the statistics for the post-2002 period.

**Solvents not at fault:** In a <http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43378&F=H>>report</a> published on 3 August in *Occupational and Environmental Medicine* US researchers have found no consistent evidence for increased risk of glioma or meningioma following occupational exposure to six chlorinated solvents they studied. However, there was some suggestion of a connection between carbon tetrachloride and glioma for exposed subjects with exposure above the median.

**Pediatric Brain Tumor Foundation:** The US-based Pediatric Brain Tumor Foundation has <http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43361&F=H>>announced</a> the selection of Robin Boettcher as the new CEO of the Foundation, commencing on 10 September. Boettcher succeeds the late Dianne Traynor who died last month and has a background of work in the National Parkinson Foundation, the Leukemia and Lymphoma Society, and the Multiple Sclerosis Society.

**The rights of parents:** In a disturbing case in the United States an eight-year old girl (Sarah Parisian) with a medulloblastoma brain tumour has had her treatment examined by a court after the treating oncologist turned in the parents to Child Protective Services for questioning her recommendations. The therapy being considered sounds like the St Jude Protocol although its name was not mentioned in the media. The parents wished to have their child undergo a more "integrative" treatment approach. A lengthy <http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43384&F=H>>article</a> in the *Washington Times* about the case appears to have been written by a cancer

treatment sceptic but the case does raise some important issues about parental rights and accepted treatment modalities which may have severe impacts on paediatric patients.

**UC Davis case:** The US *Sacramento Bee* newspaper has followed up with further [background](http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43358&F=H) on one of the neurosurgeons (Dr. J. Paul Muizelaar) involved in the UC Davis experimental infection case on brain tumour patients (reported in last month's E News), which quotes those who are supportive of the specialist and those who are not.

**PTEN and EGFR:** Researchers from the USA and Brazil have undertaken research which suggests that glioblastoma patients with PTEN (a tumour suppressor gene), modified by phosphorylation, had resistance to EGFR (epidermal growth factor) inhibitors. They are now focussing on ways to restore PTEN function in tumour cells. The research report is available on [Open Access](http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43360&F=H) in the *Proceedings of the National Academy of Sciences*.

**Etirinotecan:** Stanford University researchers will [test](http://emailcontrol.com.au/link.php?M=12927491&N=31902&L=43375&F=H) Nextar Therapeutics Inc drug etirinotecan pegol on high grade glioma patients who are bevacizumab-resistant.

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Thank you for your continuing support.

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