

<p><span style="font-size: medium; font-family: arial, helvetica, sans-serif;"><span style="font-size: medium; font-family: arial, helvetica, sans-serif;">Dear Natalya</span></span></p> <p><span style="font-size: medium; font-family: arial, helvetica, sans-serif;"><span style="font-size: medium; font-family: arial, helvetica, sans-serif;"><b><br /></b></span></span></p> <p><span style="font-size: medium; font-family: arial, helvetica, sans-serif;">If you are having difficulty in reading this version please consult the <a href="http://emailcontrol.com.au/link.php?M=15093413&N=36573&L=51259&F=H">web version</a></span></p> <p><span style="font-size: medium; font-family: arial, helvetica, sans-serif;"><b>Exciting development:</b> A consortium of 28 brain tumour researchers from institutions around the world recently published <a href="http://emailcontrol.com.au/link.php?M=15093413&N=36573&L=51268&F=H">a paper</a> on a conceptually new treatment approach for relapsed glioblastoma (GBM). The approach is called <b>CUSP9</b> which stands for <b>Coordinated undermining of survival paths with nine repurposed drugs</b>.</span></p> <p><span style="font-size: medium; font-family: arial, helvetica, sans-serif;">According to the paper's abstract, the CUSP9 treatment protocol is based on <b>a combination of drugs not traditionally thought of as cytotoxic chemotherapy agents but that have a robust history of being well-tolerated and are already marketed and used for other non-cancer indications.</b> The criteria for choosing the drugs included those that were pharmacologically well-characterised; had a low likelihood of side effect burden; showed evidence of interfering with a <b>recognized, well-characterized growth promoting element of glioblastoma</b> and when coordinated as an ensemble, <b>had reasonable likelihood of concerted activity against key biological factors of glioblastoma growth.</b></span></p> <p><span style="font-size: medium; font-family: arial, helvetica, sans-serif;">Nine drugs met these criteria: aprepitant, artesunate, auranofin, captopril, copper gluconate, disulfiram, ketoconazole, nelfinavir and sertraline. Lead author Professor Marc-Eric Halatsch (University of Ulm, Germany) said: "While the CUSP9 protocol is not clinically validated yet, a reasonable empirical and theoretical basis suggests safety and efficacy of this approach." </span></p> <p><span style="font-size: medium; font-family: arial, helvetica, sans-serif;">The IBTA has always kept as open a mind as possible with regard to new treatment approaches for GBM. We are featuring a link to the CUSP9 paper in this e-news (see above) to highlight the need to look at innovative ways of treating GBM and therefore invite our readers to share any comments they have on the CUSP9 approach. In the first instance comments for public display can be emailed to the <a href="mailto:string@hotkey.net.au">IBTA Chair</a> who will upload them to a webpage. Later, we plan to create a Bulletin-Board type webpage for automated comment if there is on-going discussion. The comments page is located <a href="http://emailcontrol.com.au/link.php?M=15093413&N=36573&L=51260&F=H">here</a> and already contains an overview from one of the IBTA's caregiver advisors. Comments by patients, clinicians, and researchers would also be welcome.</span></p> <p><span style="font-size: medium; font-family: arial, helvetica, sans-serif;"><b>Research developments:</b> US researchers, who concentrated on DNA analysis of 45 tissue samples of pediatric low-grade gliomas from seven institutions, <a href="http://emailcontrol.com.au/link.php?M=15093413&N=36573&L=51262&F=H">have found</a> that a gene called MYBL1 was rearranged and missing a part of its genetic message in nearly 30 percent of the tumors categorised as grade 2 .. Chinese researchers have <a href="http://emailcontrol.com.au/link.php?M=15093413&N=36573&L=51256&F=H">identified</

a> that overexpression of the bone morphogenetic protein (BMP) 4 ♦was significantly associated with low grade as well as the lower mortality of high-grade gliomas in survival analysis♦ ... Brain tumors were among the 22 tumor types whose gene expression data was <a href="http://emailcontrol.com.au/link.php?M=15093413&N=36573&L=51265&F=H">studied</a> by US researchers, resulting in the identification of hundreds of potential drug targets ... Using a grant of \$573,000 from the US Department of Defense an Indiana (USA) researcher <a href="http://emailcontrol.com.au/link.php?M=15093413&N=36573&L=51273&F=H">will study</a> the role of nanoparticles in targeting brain metastases caused by breast cancer ... An Italian <a href="http://emailcontrol.com.au/link.php?M=15093413&N=36573&L=51267&F=H">study</a> involving Gaetano Finocchiaro from Milan, and which used mature dendritic cells loaded with autologous tumor-cell lysates, in recurrent GBM patients, has shown promise ... A retrospective single-centre <a href="http://emailcontrol.com.au/link.php?M=15093413&N=36573&L=51276&F=H">study</a> in Germany, involving 253 newly diagnosed GBM patients, has shown that ALA-Fluorescence-guided surgery followed by concomitant radiochemotherapy, showed significantly improved overall survival in the patients.</span></p> <p><span style="font-size: medium; font-family: arial, helvetica, sans-serif;"><b>Existential dread:</b> Canadian psychologists have <a href="http://emailcontrol.com.au/link.php?M=15093413&N=36573&L=51269&F=H">identified</a> that Tylenol (acetaminophen), which is commonly used to alleviate headaches, could also be used to reduce a person♦s ♦existential dread♦ arising from such causes as thinking about death.</span></p> <p><span style="font-size: medium; font-family: arial, helvetica, sans-serif;"><b>Brain metastases:</b> The European-based on-line resource ♦ecancer♦ has published several items on brain metastases which can be accessed <a href="http://emailcontrol.com.au/link.php?M=15093413&N=36573&L=51278&F=H">here</a>.</span></p> <p><span style="font-size: medium; font-family: arial, helvetica, sans-serif;"><b>Company developments:</b> <a href="http://emailcontrol.com.au/link.php?M=15093413&N=36573&L=51277&F=H">ERC</a> (Epitopoietic Research Corporation) Belgium is appealing for funds to initiate clinical trials for its therapy which aims to simulate the immune system of glioblastoma patients ... The Dutch to-BBB Technologies B.V. brain drug delivery company will <a href="http://emailcontrol.com.au/link.php?M=15093413&N=36573&L=51257&F=H">extend</a> its phase I/IIa study of breast cancer metastases and glioma to take on two more forms of brain metastases. It has also <a href="http://emailcontrol.com.au/link.php?M=15093413&N=36573&L=51279&F=H">commence d recruiting</a> in the Netherlands and Belgium ... Agenus Inc <a href="http://emailcontrol.com.au/link.php?M=15093413&N=36573&L=51266&F=H">announced</a> apparently good PFS and OS results at the American Association of Neurological Surgeons (AANS) meeting for its Phase II trial of standard therapy and its Prophage G-100 vaccine for newly-diagnosed GBM patients.</span></p> <p><span style="font-size: medium; font-family: arial, helvetica, sans-serif;"><b>Deadlines and events:</b> The American Brain Tumor Association has advised that it has <a href="http://emailcontrol.com.au/link.php?M=15093413&N=36573&L=51274&F=H">a series</a> of brain tumor-related webinars scheduled for the remainder of the year and also have a number of past webinars <a

<http://emailcontrol.com.au/link.php?M=15093413&N=36573&L=51275&F=H>>archived</a> on its website ... Contact addresses for the 2014 Asian Society of Neuro Oncology (ASNO) meeting to be held in Istanbul Turkey are <a href="mailto:ozan.konukcu@bahcesehir.edu.tr">ozan.konukcu@bahcesehir.edu.tr</a> (scientific) and <a href="mailto:info@asno2014.org">info@asno2014.org</a> (organization) ... There are special entitlements for patient advocacy groups participating in the September European Cancer Congress in Amsterdam, including the availability of free exhibition slots for patient organisations in Patient Advocacy Square which are explained <a href="http://emailcontrol.com.au/link.php?M=15093413&N=36573&L=50766&F=H">here</a> .. The deadline for applications for eight \$1500 <a href="http://emailcontrol.com.au/link.php?M=15093413&N=36573&L=51261&F=H">scholarship</a> s</a> for non-North American medical professionals, being awarded by the Society for Neuro-Oncology (SNO) to attend the November World Federation of Neuro Oncology meeting being held concurrently with the SNO meeting, is 1 July.</span></p><p><span style="font-size: medium; font-family: arial, helvetica, sans-serif;"><b>Estimating and communicating prognosis:</b> The authors of an <a href="http://emailcontrol.com.au/link.php?M=15093413&N=36573&L=51264&F=H">article</a> in the journal <i>Neurology</i> have called for the development of a better evidence base for the ♦new science of prognostication♦ i.e. the estimation and communication of ♦what to expect♦, for patients, families and surrogates of those in neurologic care.</span></p><p><span style="font-size: medium; font-family: arial, helvetica, sans-serif;"><b>Confusing wording:</b> This is the headline in a <a href="http://emailcontrol.com.au/link.php?M=15093413&N=36573&L=51263&F=H">recent article</a> in <i>Online Pharma Times</i> - "150M euros in new EU funding for brain research". It goes on to say "At the start of its European Month of the Brain, the European Commission has announced funding of around 150 million euros for 20 new international brain research projects, bringing the total European Union (EU) investment in brain research since 2007 to over 1.9 billion euros."</span></p><p><span style="font-size: medium; font-family: arial, helvetica, sans-serif;">Later, the article states: "The 20 projects which have been shortlisted for EU funding are expected to deliver new insights and innovations in key areas such as traumatic brain injury, mental disorders, pain, epilepsy and paediatric conduct disorders. The projects cannot be named before the grant agreements are finally concluded, but all are expected to start from this summer, says the Commission, which goes on to note that industry and small business partners will have a particularly strong involvement in three of the areas - mental disorders, epilepsy and paediatric conduct disorders - to fuel innovation and real-life solutions."</span></p><p><span style="font-size: medium; font-family: arial, helvetica, sans-serif;">It is clear from the above (except for the epilepsy research, which may have some relevance to brain tumours) that the money appears to be intended for the neuroscience and neurodegenerative areas and <b><i>not</i></b> neuro-oncology. We would like to be proved wrong. The problem is that people in the general community can obtain the misleading impression that Governments are looking after brain tumours with vast amounts of money for research. It might be "brain research" but it is not necessarily "brain <b><i>tumour</i></b> research".</span></p><p><span style="font-size: medium; font-family: arial, helvetica, sans-serif;"><b>Brain tumour fraud:</b> In a <a href="http://emailcontrol.com.au/link.php?M=15093413&N=36573&L=51270&F=H">case</a> reminiscent of an earlier USA case, a 42 year-old UK female teaching assistant has been jailed

for eighteen months for fraud in claiming to have a terminal brain tumour for which she needed money to pay for treatment. Her ruse was uncovered when a head teacher wrote to a university hospital about the illness and was told she did not have a brain tumour but was suffering from tension type headaches.

**Boston bombings:** We sympathise particularly with our readers in Boston and the USA at what happened in Boston. A USA newspaper [reported](http://emailcontrol.com.au/link.php?M=15093413&N=36573&L=51258&F=H) that Anzor Tsarnaev, the father of the alleged Boston bombers, left Boston for Germany two years ago for treatment of brain cancer" and then travelled to Makachkala, the capital of Dagestan in Russia. The US National Brain Tumor Society, which has an office in Watertown, Massachusetts, near Boston, thanked their supporters and [wrote](http://emailcontrol.com.au/link.php?M=15093413&N=36573&L=51272&F=H): "We were heartbroken to learn that one of our staff members lost a loved one during this terrible course of events. We're doing everything in our power to support our colleague and her family during this difficult time. To the many members of the brain tumor community who offered their thoughts and prayers to the organization, as well as our colleague - we are forever thankful. It was a very difficult week, and your kind words of support provided strength to us all." Dr Johannes Wolf, who is featured on the cover of the 2013 *Brain Tumour* magazine and works at Tufts Medical Centre in Boston, emailed friends in the immediate aftermath that they were okay but: "One of the bomb victims was a psychology student here. He is dearly beloved by my patients. He and his wife lost a leg. One of the shooting victims today is the son of one of our nurses. They say he will survive. Most of my patients can not come to clinic today, and I am locked in the hospital until the hunt is over."

**IBTA developments:** The IBTA's 2013 edition of *Brain Tumour* magazine is in the process of distribution to our contacts in 109 countries. If you do not receive a copy in the post in the next few weeks please register your interest [here](http://emailcontrol.com.au/link.php?M=15093413&N=36573&L=49708&F=H). The IBTA has been allocated a slot in the combined patient advocacy booth (Number 5003) at ASCO (located on the route to the main food hall) during 29 May - 4 June and copies of *Brain Tumour* magazine will also be available from there. Please visit and introduce yourself to our representatives. Meanwhile, ASCO's *Cancer.net* editorial board has [updated](http://emailcontrol.com.au/link.php?M=15093413&N=36573&L=51271&F=H) its basic information about astrocytomas in childhood but has tried to utilise the language generally used for other cancers, which doesn't quite fit brain tumours. It says "A tumor can be benign (noncancerous) or malignant (cancerous, meaning it can spread to other parts of the body)."

Is a malignant primary brain tumour "malignant" because of its capacity to spread to other parts of the body? We think not. How many brain tumours do spread outside of the CNS? It is described as "malignant" because of its histopathology and molecular structure, and known characteristics and likely future course due to its classification.

Thank you for all your continuing support.

**Denis Strangman**  
(Chair and Co-Director)

International Brain Tumour Alliance IBTA

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