Dear Friends,

We hope you enjoy this month’s IBTA e-news and that it is of interest to you. In particular, we hope that you are encouraged by the wide range of research and activities taking place in the international brain tumour community.

As you can see from the long list below of forthcoming conferences and events, the clinical and research communities regularly come together in the spirit of collaboration to find better treatments. It is very encouraging to know that these collaborative events take place in a determined effort to try to improve the quality of life and outcomes for brain tumour patients.

With best wishes,

Kathy

Kathy Oliver
Treatment News

Fluorescent marker may improve glioblastoma surgery
A new study shows that fluorescence-guided surgery may improve survival in glioblastoma patients. Using 5-aminolevulinic acid (5-ALA) to highlight the tumour mass, a surgeon was able to resect more tumour than without, resulting in a better prognosis. [Read more](abstract free).

On the research front...

Gene therapy trial opens
Phase I testing of a new gene therapy approach for gliomas is now underway and [recruiting new patients](#). By using genetically engineered viruses to transfer two different genes into tumour cells, the genes are designed to induce tumour destruction and remove any residual tumour left after initial surgery. [Read more](#).

Breast cancer drugs may be ‘strikingly effective’ in brain tumours
University of Cincinnati researchers are investigating repurposing letrozole – an established breast cancer treatment – for use in gliomas after obtaining promising results from initial lab-based experiments. [Read more](#).

Animal and human study shows that bacteria injection shrinks tumours
New findings, published in *Science Translational Medicine*, show that a strain of the bacteria *Clostridium novyi* can cause tumour destruction. Following
Using nanoparticles to strike gold in brain tumour treatment
Researchers from the University of Cambridge, UK, have used gold nanoparticles combined with X-rays to target glioblastoma cells. In this lab-based study, chemotherapy-coated nanoparticles are absorbed into tumour cells and exposed to radiotherapy, inflicting localised damage to the tumour.

Read more.

Urine test to track brain tumour growth in children may be possible
A protein called netrin-1 has been found in the urine of children with medulloblastomas. Levels were highest in those with the most aggressive tumours and fell after treatment, indicating that urine protein levels could serve as a non-invasive way to screen, monitor and even predict tumour growth.

Read more.

Gene test could predict brain tumour type
Research published in Oncotarget has shown that the aggressiveness of a brain tumour is related to a person’s genes. Within what was thought to be ‘junk DNA’, numerous ‘microsatellite’ regions were identified as being markers for different glioma types.

Read more.

Study hints that antidepressant medication may treat medulloblastoma
Published in Nature Medicine, research has further defined the role of the GNAS gene in driving medulloblastoma tumour growth. Gene changes seen in a subset of tumours (Sonic hedgehog-driven human medulloblastomas) suggest that the antidepressant drug Rolipram could be a future treatment.

Read more.

And briefly...

It could be time to reconsider glioma genesis according to research
published in *Cancer Cell*, which shows that major genetic changes occur early, rather than late, in a tumour’s growth. Read more.

“Magnetic hyperthermia” offers a novel cancer treatment by using genetically engineered bacteria to deliver metal particles to a tumour before heating with an intense magnetic field. Read more.

New, affordable 3D tissue culture method developed at the University of Nottingham, UK, and published in *PLOS One*, enables rapid growth of tumour-like tissue ‘balls’ for early drug testing. Read more.

Handheld scanner could give surgeons real time assessment of tumour removal with the development of a small Raman scanner that detects a nanoparticle contrast; a technique so far tested on mice in simulated glioblastoma surgery. Read more.

Biochip system to offer faster genetic testing of brain tumours for MGMT gene methylation – one of the key prognostic markers for glioblastomas. Read more.

Compound is developed that deactivates a potential tumour growth regulator called NEU4, which is an enzyme located on the cell surface of glioblastomas, in a finding that could potentially lead to new drug development. Read more.

Russian neurosurgeons and software engineers develop software that will predict tumour growth through analysis of consecutive MRI scan results. Read more.

Company news

Novocure’s portable NovoTTF™-100A is on fast track for pre-marketing
approval in Japan after being granted the ‘High Unmet Medical Need’ designation by the Japanese Ministry of Health and Welfare. Read more.

NW Bio reports on Phase III trial of DCVac®-L and that 55 patients with glioblastomas who are not eligible to enrol in the trial due to unusually rapid recurrence have received the treatment in a compassionate use “Information Arm”. Read more.

Insys Therapeutics’ cannabinoid agent receives US FDA orphan status for potential treatment of glioblastoma. Read more.

News from other organisations

Long-term glioblastoma survivor research wins American Brain Tumor Association grant
In association with the Brain Tumor Funders’ Collaborative (BTFC), the American Brain Tumor Association (ABTA) have awarded a $2 million grant for research that will aim to understand the basis for survival in glioblastoma patients who live longer than 5 years from diagnosis. Read more

Forthcoming webinar: the ketogenic diet
Leonora Renda, RDN, of University of Arizona Cancer Center, will be presenting a free educational webinar discussing the potential role of the ‘ketogenic diet’ in brain tumour care. Organised by the American Brain Tumor Association (ABTA), the interactive online event will take place on Wednesday 8th October at 1 – 2 pm Central Daylight Time (7- 8 pm GMT). Registration for the online event is open here.

The top 10 unanswered research questions? You decide!
Readers will remember from past editions of the IBTA e-news that we asked you to help complete a survey organised by the UK based James Lind Alliance (JLA) Neuro Oncology Priority Setting Partnership (PSP). The Neuro Oncology
JLA PSP is now asking for help with the next stage of the process to achieve a ‘Top Ten’ list of unanswered questions in brain and spinal cord tumour research. Over 600 questions were submitted in the first round and this has been reduced down to 44, taking into account duplicate questions and questions which have already been answered by previous research.

Voting is open in any country, and we invite patients, carers, relatives and clinicians to select the ten questions that they think should go in the final list. Vote now and read the full story at www.neuro-oncology.org.uk. The survey will be open until Monday, 13th October.

IBTA news

Official IBTA 2013 Summit Report now available online
Developed and hosted by the International Brain Tumour Alliance (IBTA), the inaugural World Summit of Brain Tumour Patient Advocates brought together over 60 key representatives of brain tumour charities and not-for-profits from 20 countries.

Held at Lafayette, California, USA, on 18 - 20 November 2013, the official report is now available for reading and downloading. Click here.

Raising awareness: 2014 global ‘Walk’ and ‘Week’ activities
Don’t forget that The International Brain Tumour Awareness Week is from 26 October to 1 November 2014. The IBTA would love for you to organise an awareness-raising event in your locality, region or country – just please let us know your plans!

And throughout 2014, ‘The Walk Around the World for Brain Tumours‘ is uniting the international brain tumour community in a common goal – raising awareness of the challenges of brain tumours and raising funds for research and support.
For more information visit [www.theibta.org](http://www.theibta.org) or for regular updates visit our [Facebook page](http://www.facebook.com). To register your interest for either activity, please email [kathy@theibta.org](mailto:kathy@theibta.org) or simply reply to this email.

**Demystifying palliative care**

In this month’s *European Association of NeuroOncology Magazine*, IBTA Chair Kathy Oliver discusses the public perception of the term 'palliative care' and how crucially important it is to promote clarity and consistency in the way palliative care is described to patients. Read her article in full [here](http://www.theibta.org). Wolfgang Grisold’s accompanying editorial can also be read [here](http://www.theibta.org).

**Conference Report**

**British Neuro Oncology (BNOS) 2014 conference**

A report of the BNOS conference held from 9-11 June, in Liverpool, UK is now available for reading online [here](http://www.theibta.org).

**Upcoming conferences and events:**

**Sep–Nov 2014**

Here are a selection of upcoming conferences and events. For other conferences during the September, October and November period, please see the IBTA website conferences page [here](http://www.theibta.org). If you are aware of a brain tumour-relevant conference - including any patient conferences - that we have not yet listed on the IBTA website then please let us know.

**SIOPE–ENCCA Conference 2014 – "Joining Efforts for a Brighter Future for Children and Adolescents with Cancer**

18-19 September 2014

Brussels, Belgium

**The 9th European Oncology Nursing Society Congress (EONS 9)**
18-19 September 2014
Istanbul, Turkey

**4th Annual Brain Metastases Research and Emerging Therapy Conference**
19-20 September 2014
Marseille, France

**39th European Society for Medical Oncology (ESMO) Congress**
26-30 September 2014
Madrid, Spain

**The Royal Marsden Neuro–Oncology Conference**
2 October 2014
London, UK

**11th EANO Congress**
9-12 October 2014
Turin, Italy

**46th Congress of the International Society of Paediatric Oncology**
22-25 October 2014
Toronto, Canada

**7th Annual Scientific Meeting of the Co–operative Trials Group for Neuro–Oncology (COGNO)**
24-25 October 2014
Melbourne, VIC, Australia

**34th ESSO Congress in partnership with BASO 2014**
29-31 October 2014
Liverpool, UK

**CNS Anticancer Drug Delivery and Development Conference**
12-13 November 2014
Miami, Florida, USA

19th Annual Scientific Meeting of the Society for Neuro-Oncology (SNO 2014)
13-16 November 2014
Miami, Florida

STOP PRESS: International Pathology Day: 5th November 2014
The 5th of November will be the first annual International Pathology Day. This is an opportunity for pathologists to celebrate their work with the public. Individuals and organisations are invited to register an event in their area. Public engagement events will be taking place in schools, hospitals, science centres and cafés. To find out more or register an event click here.

And finally...

Update on Ashya King story
We are delighted at the news that Ashya King - a five-year-old medulloblastoma brain tumour patient from the UK - has been reunited with his parents. In a story widely publicised by the British press, Ashya’s parents were arrested in Spain after they removed him from an English hospital to take him for proton beam therapy abroad. A judge in Spain ordered their release and at time of writing Ashya is due to receive treatment in Prague, Czech Republic. Read more here and here.

Challenging brain tumour operation in Kazakhstan
Surgeons of the National Center for Neurosurgery in Astana have conducted surgery to remove a brain tumour close to the motor cortex - the area responsible for movement. The patient remained awake throughout the three hour operation and made a good recovery after surgery. It was the first time such an operation has been performed in Kazakhstan. Read more.

Duke University neurosurgeons operate in Uganda
As part of Duke University’s ongoing neurosurgical twinning programme with
New Mulago Hospital, Uganda, a recent neurosurgical camp attracted local media attention after brain tumour surgery was performed on patients who would otherwise have been unable to afford treatment. Watch more (video).

ABOUT THE IBTA

Who we are

The International Brain Tumour Alliance was established in 2005. It is a network of support, advocacy and information groups representing brain tumour patients and carers in different countries and also includes researchers, scientists, clinicians and allied health professionals who work in the field of brain tumours. For more information, please visit www.theibta.org.

Tell us what you think!

We love to hear from you if you have any news that you would like to share with the IBTA community. Just send us an email: chair@theibta.org. We will do our best to relay as much information as possible to our subscribers via this monthly newsletter and our website. The selection of e-News entries is at the sole discretion of the editors.

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