



BRAIN TUMOUR ALLIANCE AUSTRALIA Inc.

BTAA eNews April 2015

Dear friend of the brain tumour patient and caregiver support community

After a three month hiatus, the BTAA eNews is back for 2015.

The previous [BTAA eNews from December](http://tinyurl.com/noukbce) is available at <http://tinyurl.com/noukbce>

The focus of this month's eNews is the 2015 Brain Cancer Action Week educational and support forums in Sydney and Melbourne, Friday 8 May 2015, during Brain Cancer Action Week (3 to 9 May 2015).

Registrations are now being taken for these free events.

Sydney forum

Register at: <http://tinyurl.com/oslajau>

Date: 8 May 2015 10:00 am

Location: The Menzies Hotel , 14 Carrington Street, Sydney, NSW

Organisers/Hosts: NSW Cancer Council, Cure Brain Cancer Foundation, SNOG, Brainstorm.

Draft program (<http://tinyurl.com/o3yeumg>) **includes:**

***Welcome (10 am):** Dr Jonathon Parkinson

***Keynote presentation:** "Overview of brain tumours including current treatment and research developments", presented by Neurosurgeon Jacob Fairhall.

***Panel discussion:** Drs Kerrie McDonald, Helen Wheeler, Eng-Siew Koh, and Jacob.

***Parallel session 1:**

1) 'Supportive Care' - "Common issues in brain tumour patients", presented by Marina Kastelan, and psychological aspects by a presenter TBA (Chair: Kaye Duffy).

2) 'What do all these tests mean' - "Tests related to diagnosis: Pathology and biological markers", presented by Dr Michael Buckland, and "Research development and early phase clinical trials", presented by Dr Kerrie McDonald (Chair: Dr Jonathon Parkinson).

***Parallel session 2:**

1) 'Support for families and carers' - "Update on research", presented by Michelle Stewart, and "Cancer Council NSW services to brain tumour patients and their families", presented by Lorna O'Brien (Chair: Kaye Duffy).

2) 'Recent advancements in clinical care' - "Update on radiotherapy", presented by Dr Cecelia Gzell, and "Update on chemotherapy", presented by Dr Helen Wheeler.

***Meet the experts** (3:20 to 4:00 pm)

Melbourne forum

Register at: <http://tinyurl.com/nrr4q2y>

Organisers/Hosts: Cancer Council Victoria and partner brain tumour organisations

Date: 8 May 2015 9:30 am (forum itself runs 10 am to 3 pm)

Location: Cancer Council Victoria, Level 3, 615 St Kilda Road, Melbourne

Draft program for the forum can be found at: <http://tinyurl.com/o3yeumg> and includes:

***On-site registrations** (9:30 am)

***Sessions** (10 am to 3 pm)

- The latest in clinical trials research and the role of the Clinical Research Nurse.
- The in's and out's of seizure management.
- Practical challenges: returning to driving, financial and legal issues, resources for respite.

A marketplace of organisations with information and resources will also be available.

For further info, email clinicalnetwork@cancervic.org.au

Further [updates on events](#) during Brain Cancer Action Week can be found at www.btaa.org.au/events

Brain Cancer Action Week started in NSW in 2010 as a partnership between the Cancer Council NSW and partner organisations, and now is recognised nationally and includes other organisations, including BTAA.

BTAA Newsletter, April 2015

This hard copy BTAA newsletter, with different content to the eNews, is mailed each quarter (three months) to BTAA members, supporters, and other contacts. Please contact secretary@btaa.org.au if you have not been receiving these. The latest edition has been posted to all contacts, [but is also available online](#). see www.btaa.org.au/news/26/btaa-news-brain-cancer-action-week-may-2015

Summary of selected news items from around the world

[International Brain Tumour Alliance \(IBTA\) \(theibta.org\)](#)

January IBTA e-news [selected items]

<http://theibta.org/ibta-e-news-january-2015-3/>

- [Cochrane Collaboration reviews irradiation-induced cognitive impairments in brain tumour patients.](#)

'The Cochrane Collaboration has published a systematic review that assesses the effectiveness of interventions for preventing and ameliorating radiotherapy-related cognitive impairments. Key review findings include that donepezil may help patients with primary brain tumours who receive radiation therapy.'

- [IBTA advisor writes about four radical therapies that could treat his brain tumour](#)

'In last week's New Scientist, IBTA's Digital Technology Advisor, Dr Stuart Farrimond, writes about four new glioblastoma therapies (Nanotherm, NovoTTF-100A, DCVax and VB-111) and their potential to treat his brain tumour in the future.'

February IBTA e-news [selected items]

<http://theibta.org/ibta-e-news-february-2015/>

- [Surviving Terminal Cancer film premieres in London, New York and online](#)

"Surviving Terminal Cancer" is a documentary following the story of Ben Williams (a glioblastoma survivor who was diagnosed in 1995) and other long term brain tumour survivors. This privately-funded film premiered in London on February 4th; New York on February 18th, and is now available for free streaming online.'

- [New online tool lets brain tumour patients search for specialist neurosurgeons](#)

'The Subcortical Surgical Group (SSG) has launched their online 'Physician Locator',

a tool to let US patients find local surgeons with expertise in using new surgical technologies and approaches.'

[March IBTA e-news \[selected items\]](#)

<http://theibta.org/ibta-e-news-march-2015/>

- [Cancer drug first tested on dogs to enter human trials](#)

'A phase I clinical trial of a potential new glioblastoma treatment, PAC-1, has started recruiting patients. The drug, which was first tested on dog malignancies, appears to penetrate the blood-brain barrier and is expected to work alongside other cancer treatments.'

- [Improving doctor-patient communication: clinical study now recruiting](#)

A study evaluating communication between physicians, glioblastoma patients, and caregivers is now recruiting participants at three locations in New York and New Jersey, USA. The study will look at how oncologists can best provide information about brain tumours, results and treatments. [Read more.](#)

[American Brain Tumor Association \(www.abta.org\)](#)

Regarding online news items, it's also been a quiet three months from the world's largest (albeit operating solely in USA) brain tumour patient support and advocacy organisation. The last ABTA eNews appears to have been in December, although the ABTA blog and Twitter accounts have remained active with several items per week. See [@theABTA](#) for updates.

[National Brain Tumor Society \(www.braintumor.org\)](#)

[February News & Updates \[selected item\]](#)

- ['BRAIN TUMOR PATIENT & CAREGIVER SURVEY' \[2014\]](#)

*1851 participants, 54% were caregivers and 46% were patients.

*'Top priorities or future brain tumor treatments':

1. Retain brain functioning
2. Maintain ability to walk and perform basic tasks
3. Reduce pain, including headaches.'

See: <http://tinyurl.com/pgaozrm>

[Cure Brain Cancer Foundation \(www.curebraincancer.org.au\)](#)

[Research Blog Posts \[selected items\]](#)

- [Naomi Cook's experience](#) with doses of oxytocin (aka "the love chemical") and her daughter's hypothalamic obesity from a craniopharyngioma.
<http://tinyurl.com/lvz4dnw>
- [Discussion of recent and ongoing trials](#) overseas that test whether metabolic therapies, such as ketogenic diets, help to reduce or slow brain tumour growth.

- <http://tinyurl.com/mocg5p6>
- This had been missed in previous BTAA eNews, but better late than never: A literature review published by CBCF on May 2014, by Drs Sarah McKay & Ruth Hadfield, titled '[Current Knowledge in Brain Cancer Research](#)'.
<http://tinyurl.com/oma59og>
 - [Pharmacy Guild of Australia and CBCF announce their new partnership to promote earlier detection of brain tumours and increase research funding](#): 'The Guild will be doing more to help, both as a national body and through encouraging community pharmacies around Australia to raise awareness about brain cancer and the need for research funding.'
<http://tinyurl.com/plmb8nx>
 - [Cross posted from SickKids Canada](#): Researchers at SickKids Canada undertook a retrospective study of children's outcomes with Rhabdoid brain tumours, and found that in patient's with particular gene expression profiles, high-dose chemotherapy without radiation improved survival by 40 to 50 percent over the standard chemotherapy and radiation treatment: 'The study is published in the April 14 online edition of The Lancet Oncology'.
<http://tinyurl.com/ocgkrya>
 - '[Ben Leske's journey with cancer](#)': "I have learned to live for every moment, to use my gifts to their fullest and in ways that improve the lives and experiences of those around me. I look back on my time after diagnosis with very few regrets. I'm grateful for every day I have in this place and believe I have many more before me". See <http://tinyurl.com/p9hqz69>

Update on Optune

The mystery of the reaction to the Optune (formerly the "NovaCure TTFields therapy" device) Phase III trial results as a first-line treatment of glioblastoma continues, with no further statements from the larger research/advocacy brain tumour organisations since December.

Reaction to the [BTAA special announcement of November](#) (<http://tinyurl.com/npop78m>) on the results from 2014 SNO Annual Scientific Meeting were generally muted, not least from the long-suffering BTAA management committee which again remarked on the importance of being shown drafts before sending BTAA eNews editions (sorry again colleagues!.....).

A summary of the various remarks from other readers, some of whom were clinicians, is as follows:

- There was no indication the company was pressing approval in Australia, at least that this stage.
- The use of the device and/or the device itself is extraordinarily expensive, at least as of the minute.
- The extent of benefit has not yet been demonstrated, despite FDA agreeing to the early termination of the trial.

- The proposed strategy in the eNews was "interesting" (Note: When someone says they think something is "interesting", and don't elaborate, you can probably guess that they are in fact not at all interested in it).

However, there were a few favourable responses to the proposed strategy to get Australian patients access to Optune, all of which were from patients/survivors.

The company announced in late December that Optune was available at over [150 treatment centres in the USA](#). In late March, it announced that Optune had been [approved for use in Japan](#): 'Approval allows for rapid, direct commercial market access in Japan, the world's second largest medical device market'.

See: <http://tinyurl.com/kgcdacr>

And: <http://tinyurl.com/m9l7e9s>

The whole situation seems a bit mysterious, but more information will inevitably come out sooner or later.

Mel goes Grey in May

Brain tumour survivor Mel Johnson is again generously donating her time and energy to [host a fundraising dinner](#) for BTAA and Brainstorm.

Date: 30 May 2015

Venue: Bathurst Panthers, NSW

Further details are available at: www.btaa.org.au/events/6/mel-goes-gray-in-may

Many thanks again Mel for all your efforts!

Support is available

For those facing a brain tumour diagnosis or its aftermath, practical support is available from your peers in local support groups, cancer control Government agencies, Cancer Councils and other NGOs, and teams of clinicians and allied health care specialists. Many skilled professionals working on future treatments, from person-centered quality of life researchers to scientists studying why tumours develop and how we can best remove them. **To talk with experienced caregivers, call BTAA on the Freecall number: 1800 857 221, and see [support groups available in your local area](#) at: www.btaa.org.au/page/26/support-organisations**

BTAA thanks its donors (**especially you, Mel!**). **We are a volunteer-only organisation that receives no funding or concessions from any governments, asides from indirectly as donations to us are tax deductible.** Your funds continue to help grow the organisation and each day it is more capable, committed and able to assist to patients and caregivers.

Thank you for reading.

Matt Pitt (MPH, BBiotech [Hons], both from ANU)
Chair, Brain Tumour Alliance Australia
btaa.org.au

BTAA on social media

Facebook: [Brain Tumour Alliance Australia](#)

Twitter: [@BrainTumourAA](#)

Youtube: Search 'BTAA' for various videos

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Note: After a three year hiatus from its monthly eNews service, it was resumed based on feedback from convenors' of Australian support groups that such information assists their work. The eNews is normally sent on the morning of the first Friday every month. BTAA welcomes feedback on the content and format of these eNews services. **Please contact secretary@btaa.org.au. In the near future, there will be an option to notify us of your preferences and only receive select topics of interest to you.**

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