

BTAA newsletter

Special edition to mark the Sydney Forum 8 March 2012

Welcome to the Sydney Brain Tumour Patient and Carer Forum

On behalf of Brain Tumour Alliance Australia (BTAA) I would like to thank the Sydney Neuro Oncology Group (SNOG) for co-sponsoring this event. I particularly acknowledge the efforts of Dr Eng-Siew Koh from Liverpool Hospital and Allison O'Dea from the Sydney Neuro Oncology Group together with BTAA Secretary Denis Strangman in bringing this day together. And a special thanks to North Shore Private Hospital for the catering and the Kolling Institute for use of its meeting rooms. We will be uploading video of the highlights of today's speakers to www.btaa.org.au

And thanks to BTAA members Renee Hindson, Sarah Mamalai and committee member Mark Dalliston for sharing their wisdom in this issue. I am inspired by their stories.


I am pleased to introduce BTAA's newest committee member, Kelly Webster. Kelly has been helping BTAA to give patient, family and care givers voices through the effective use of social media to share knowledge and information no matter where they live. You can contact Kelly on sydney@btaa.org.au



BTAA new committee
member Kelly Webster.



I hope you enjoy the forum. Please take the time to give us some feedback on the forum on the form provided or email me – chair@btaa.org.au I would also like to hear from you if you have stories for the next e-news.

You can also follow and interact with us on  'Brain Tumour Alliance Australia' to hear about our latest activities and up coming initiatives.

Regards

Matt Pitt
Chair
Brain Tumour Alliance Australia Inc.



About Brain Tumour Alliance Australia (BTAA) Inc

- Brain Tumour Alliance Australia (BTAA) is the only national brain tumour patient and caregiver organisation in Australia.
- It was established in late 2008 by a group of brain tumour patients and current and former caregivers.
- BTAA is concerned about all tumours (neoplasms) of the central nervous system (CNS), which includes the meninges, brain and spine.
- Whilst welcoming the advice and input of health care professionals, BTAA seeks to represent the brain tumour community from the viewpoint of the patient, family and caregiver. BTAA is incorporated in the Australian Capital Territory.
- BTAA coordinates and liaise between organisations, groups and service providers with an interest in central nervous system tumours.

BTAA is a voting member of the Consumers Health Forum of Australia. www.chf.org.au/our-members.php
The BTAA constitution is available on www.btaa.org.au

BTAA has been endorsed by the Australian Taxation Office as a Deductible Gift Recipient.

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International Brain Tumour Awareness Week



The Prime Minister wears a grey ribbon provide by BTAA in the House of Representatives to mark International Brain Tumour Awareness Week 2011 which was held during 30 October – 5 November 2011.

BTAA has supported the establishment of a Parliament Brain Tumour Awareness Group convened by Senator Catryna Bilyk (ALP, TAS) and Senator Scott Ryan (Lib, Vic).

www.aph.gov.au/About_Parliament/Parliamentary_Friendship

Brain Tumours, Depression and anxiety orders

In 2010 Senator Bilyk hosted the launch of the BTAA/beyond blue fact sheet on Brain Tumours, Depression and Anxiety disorders. Several experts in the area contributed to the development of the text of the Fact Sheet. One of those contributors was Associate Professor Jane Turner from Brisbane who wrote prior to the launch:

"Coping with a brain tumour is challenging enough but when depression or anxiety are superimposed the situation can seem overwhelming. Unfortunately many people with brain tumours and their family members struggle with this double whammy because of the tendency to overlook depression and anxiety as disorders which require treatment, instead believing that feeling upset or down is normal. Whilst some distress is almost inevitable, distress that undermines the ability to be with and share in relationships and family life is not normal and deserves treatment."

Sydney Radiation Oncologist Dr Eng Siew-Koh also contributed to the drafting process, together with Dr Ally Rooney of Edinburgh, Scotland.

BTAA member Sarah Mamalai told the launch audience that depression was like the 'dirty secret' of brain tumour diagnosis and treatment. She said "We weren't warned to be vigilant to the signs of depression which can be triggered by the diagnosis itself or by the intensive treatments themselves – no wonder my poor brain snapped."

Sarah said "three months after commencing my chemo (two chemo protocols plus steroids) plus radiation, my diagnosis and treatment triggered a severe psychotic episode and a deep depression.

Sarah spoke out to tell patients that even on the darkest of dark days there is always a tiniest of tiny glimmer of hope – and to grasp it.

BTAA appreciates Sarah's courage in telling her story. The late Peter Veness of AAP recorded a film interview with Sarah that day and it is available on www.sarahmamalai.com



Sarah is planning the Brain Storm Concert to raise funds for Cure for Life, Ronald McDonald House and BTAA in 2013.

Contact beyond blue for copies of the Fact sheet No. 46. 1300 22 4636

Sarah Mamalai supports BTAA and the members of the ACT brain tumour support network. This photo was taken in 2010 and shows the annual working bee to make the 222 ribbons for the Federal parliamentarians to wear to mark International Brain Tumour Awareness Week.

Caption: (L to R) seated: Susan Pitt (Vice Chair, BTAA), Yvonne Anthoney, author Dainere Anthoney, Steve Anthoney, bear, Tracey Kristiansen, Sarah Mamalai, standing: Gregory, Denis Strangman (Secretary BTAA).

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Life after standard treatments

By Mark Dallison, Committee member, BTAA

One of the hardest things was finishing my medical treatment. I felt lost. I was lucky to be alive, but it didn't exactly feel that way. I needed to explore and find out more information. My doctors had provided no additional options.

So I embarked on researching on the Internet. From my job I thought I had a good grasp of the weird and wonderful claims on websites. My initial plan was to reinforce any healthy living tips. I increased my supplements and vitamins, most of which I have subsequently stopped taking.

Reading forums, I got the impression that there are certain sections of the cancer community wanting their cake and to also eat it. Rather than seeking some magic, my feeling is they could benefit from basic lifestyle choices.

Non medical treatments usually compromise complimentary or alternative medicines. I have remedial massage which helps my hemiparesis. There are many other complementary therapies like meditation, acupuncture and yoga. Among the best are appropriate forms of exercise and good nutrition.

Alternative treatments have come under the spotlight recently. Some are unproven but patients report satisfaction with the treatment. Others cost a lot of money and have ended in poor outcomes. Not all alternative treatments are effective, but there is the rub – how do you tell?

Such websites report success stories. Apparently, most of them report no failures. They have glowing testimonials too. But often they over reach, claiming they can cure cancer. Remember whatever their motives they are trying to sell you something. I understand very well the need to regain some control over your life.

At first it feels like you are on a medical rollercoaster. Eventually some order and control is restored. One example of this happening to me was when I got my car license back.

Change is a natural part of this process, but I try not to throw out the good with the bad. I wanted to change some things that I thought may lead to the delay of recurrence or progression. I started with nutrition. I have reviewed the various 'cures' on offer. They all appear to have little evidence supporting them, apart from testimonials which may have been written by anyone. Another thing that most of them had in common is that they were expensive. I was not willing to risk the family home on something unproven.

One thing I feel is underrated is preventing side effects. If I can prevent inflammation especially with simple things like diet and exercise, then I am giving myself the best chance of a higher quality life, increased energy and strength.

You need to exercise a great deal of caution when choosing treatments. I believe in informed choice with medical and non medical treatments. If you feel tempted to try something different – sleep on it, talk to others and think about the consequences if it doesn't work for you.



Mark and his daughter Cara with Teddy.

Over nearly five years as a survivor I have made mistakes and wrong turns. I tried one complimentary treatment with three different therapists before I realised it was a wrong turn. However, these mistakes didn't cost a lot of money or more importantly, my health.

I now believe amongst the most underrated treatments are simple effective lifestyle choices.

The website Quackwatch provides a list of dubious treatments as a reference.

www.quackwatch.com

Read Mark's article "Fitness to drive for brain tumour patients"
www.btaa.org.au/Driving.html

BTAA's submission to the 2012 Federal Budget

BTAA's submission to the 2012 Federal budget again calls on increased funding for brain tumour care coordinators and improved data amongst a range of initiatives.

The key recommendation is to provide funding to support increased access to brain tumour care-coordinators to assist brain tumour patients, and their carers, to navigate, and deal with weaknesses and challenges in the Australian health care systems, both public and private.

Policy response recommendations:

1. Central nervous system tumours (including brain tumours and other central nervous system tumours [malignant and benign]) be recognised **as an Australian Government national health priority**, in collaboration with the State and Territory Governments, as an initiative to focus public attention and health policy on the significant burden of this disease in Australia in terms of incidence, and person life years lost. There is potential for significant gain in terms of the quality of life of both patients and families, and their contribution to Australia.
2. That the Australian Government provide funding of **\$12 million over four years (\$3 million per annum)** commencing in 2012–13, for the creation of an additional 25 – 33 Full Time brain tumour care coordinators to take the total to approximately 40 FTE brain tumour care coordinators in Australia. This number is considered to be sufficiently low to ensure full utilisation of their services and not waste health care expenditure, yet make a meaningful impact to the lives of most Australians diagnosed with a brain tumour.

A copy of the full submission including extensive statistical appendices is available by emailing chair@btaa.org.au

International Brain Tumour Awareness Week 28 October – 3 November 2012



In 2011 BTAA Committee member MaryAnne Rosier organised the inaugural "Wear a Hat for BTAA For a Day" project which attracted participants from various locations. Get inspired – read the report on 2011 at www.btaa.org.au/2011WeekA.html

Mark your diary for this year's International Brain Tumour Awareness Week which runs from 28 October – 3 November 2012. But you can stretch it out to include a hat day on Melbourne Cup day – Tuesday 6 November 2012.

Interested in organising a hat day to raise funds to help support those affected by brain tumours?

Email fundraising@btaa.org.au to receive the kit. The kit will include fashion tips from the Wear a Hat for a Day for BTAA patron – milliner Christine Waring www.christinewaringmillinery.com.au/



BTAA committee member MaryAnne Rosier and her dog Basil.



Milliner Christine Waring.



Yvette Chen of Melbourne held a hat day in her office at Melbourne University Research Office.

Renee's Brain Wave 2011 Gala Dinner and Charity Auction



Renee Hindson (L) with her sister Melanie Spilker (R) and Dan Ashcroft.



(L to R) Mary Koziara and Dr Brindha Shivalingham.

Renee's story

"I've heard it said that you only walk on this world twice. Once before you get cancer and once after. It is true that a diagnosis of cancer will change a person irrevocably. But the day my world changed wasn't a day, rather a series of events.

I was skiing with a group of colleagues. It was a beautiful day, we were in high spirits. I remember looking to the blue sky and wondering how God made it come to pass that I was on such a high with a bunch of people I barely knew, miles from home in the middle of the week. Then I fell. Badly. Four days later a CT scan discovered a mass on my brain (a fortuitous discovery, not caused by the ski accident). 2 CT scans, 3 MRIs and a month of different diagnoses later I was referred to the brilliant and humble Dr Brindha Shivalingham at RPA. She took one look at my MRI and diagnosed a glioma, a tumour of the brain's glial cells.

There are over 100 types of brain tumour, benign and malignant. Malignant gliomas have a particularly poor prognosis with close to 100% of patients eventually succumbing to the disease. I guess it is for this reason that we don't really talk in terms of a cure yet. What many people will not appreciate is that even benign tumours can also be life threatening and leave the patient with a host of issues or deficits caused by treatment.

Two months later I had an 8 hour surgery to remove the tumour. Five days later the results were back, my tumour was malignant. Dr Google said the average survival was 2-5 years. All cancer causes emotional turmoil, financial pressure and even physical problems. Brain cancer, and its treatment, surgery, radiation and chemotherapy, also attacks at the mental status of a patient. These things may not be immediately apparent, or apparent only to those quite close to the patient, but they can range from deficits, like I have, in executive functions like short term memory loss, difficulty with complexity or understanding, or working with numbers. They can be changes to the personality, as well as sensory loss or loss of movement or bodily control.

As a single parent of a then 3 and 4 year old, I was devastated. I cried, I hugged

All cancer causes emotional turmoil, financial pressure and even physical problems. Brain cancer...also attacks the mental status of a patient.

my family, I drank the good champagne. And then I got angry. I felt very alone and very unsupported. Along the way I found the BTAA, who have provided information, a support group and inspirational survivors.

So I am now forever changed and walking this earth for the second time, and want to achieve something. I read a quote somewhere "What we have done for ourselves alone dies with us; what we do for others and the world remains and is immortal." I want to thank from the bottom of my heart those that have donated products and services, time and support for this event. What I achieve through this event may be a drop in the ocean, but without it – the ocean would be missing something. That's my Brain Wave."

Renee Hindson

www.gliomaaction.com/index.html

Renee's story appeared on the RPA TV show. Her parents Catherine and Bill are BTAA committee members.

BTAA would like to thank Renee Hindson – host of the Brain Wave 2011 Gala Dinner and Charity Auction held on Thursday 3 November 2011 at the National Press Club. Renee raised \$40,000 which will directly benefit brain cancer research, through the Cure for Life Foundation, and brain tumour support and advocacy through the Brain Tumour Alliance Australia. The event was filmed for TV and will appear on RPA Where are they now?

BTAA maintains a list of support groups – here are some of those listed on our website:

Location	Organisation	Contact
National	Brain Tumour Alliance Australia	1800 857 221 info@btaa.org.au
	Cancer Council	13 11 20 www.cancerconnections.com.au
NSW	Sydney hospitals – various	www.btaa.org.au/support_groups.html
	Hunter Brain Tumour Network – Kaye	kduffy@hunterlink.net.au
Victoria	BrainLink Services Ltd – Carolyn	www.brainlink.org.au admin@brainlink.org.au
	Grey Matters (benign and low grade) – Janet	thegreymatters01@gmail.com 0422 639 993
	Brain Tumour Ahoy – Low Grade	www.braintumourahoyhoy.org
Queensland	Brain Tumour Support Service – Sarah	Ask via Cancer Council National Helpline on 13 11 20
	Gold Coast – Peter	petershark72@hotmail.com 0422784885
South Australia	Adult Brain Cancer Support Association	andy.stokes@sa.gov.au or search Facebook
Western Australia	Brain Tumour WA	news@braintumourwa.com : braintumourwa.com/go/
Australian Capital Territory	ACT Brain Tumour Support – MaryAnne and Susan	vicechair@btaa.org.au
International	Worldwide listing of patient groups	www.theibta.org/websitelinks.html

Other	Category	Contacts
Specific	Pituitary	www.pituitary.asn.au
	Acoustic neuroma	www.anaa.org.au info@anaa.org.au
Teenagers and youth	CanTeen	1800 226 833
Children and young people	Red Kite	redkite.org.au
Other	Brain Foundation	brainfoundation.org.au
	Sydney Neuro Oncology Group	c/- ODeaA@ramsayhealth.com.au

Help BTAA build this list – email info@btaa.org.au

ACT brain tumour support network meeting
(L to R) Denis, Tracey, Brian, Angie, Susan, MaryAnne with Basil and Danny.



BTAA needs your support to grow.

BTAA seeks to:

- provide information to newly diagnosed patients, their family and caregivers;
- guide improvements to brain tumour research, treatment and care;
- ensure that health consumers receive treatments that are based on the best available evidence;
- raise awareness and make recommendations to governments about policy and priorities for brain tumour patients; and
- guide government and health professionals in brain tumour policy and programs.

The BTAA committee are all unpaid volunteers. BTAA receives no government funds.

Donate time to BTAA

Contact Matt Pitt on chair@btaa.org.au if you can help BTAA by raising awareness in your community. Maybe you can organise a Wear a Hat for a Day for BTAA during International Brain Tumour Awareness Week in 2012. Maybe you can put some of our brochures in your hospital. Maybe you can help with our campaign for brain tumour care coordinators. We need to form a grey army and BTAA needs your help. You can even help us by Liking or Friending our site on Facebook.

New Sydney Group

BTAA is forming a new group in Sydney to help advocate for the needs of brain tumour patients and their carers, led by BTAA committee member Kelly Webster.

Kelly writes:

Originally from Scotland, I have been living in Sydney's Eastern Suburbs for the nearly 5 years and recently attained my permanent residency in Australia.

I am a previous family member and caregiver to my mother who was diagnosed with an Oligodendroglioma and survived 7 years before losing her battle in 2010.

Joining BTAA has given me the opportunity to advocate for more understanding, better support and ongoing education in what I believe to be a neglected area.

If you are based in NSW and interested in supporting BTAA please feel free to contact me via email: sydney@btaa.org.au



BTAA committee member Kelly Webster with her mother Penny.

Donate \$ to BTAA

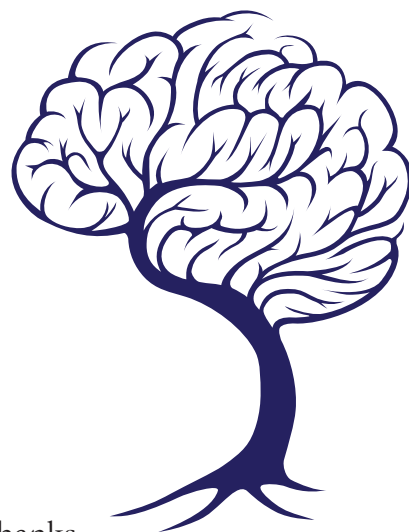
Donate to
Brain Tumour Alliance Australia Inc:
Account name:
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Commonwealth Bank
BSB: 06 2900.
Account Number: 10603153.

When making a transfer please also send an email to secretary@btaa.org.au notifying us of the transfer and your name and address if you require a receipt. Join Debbie and Dianne and donate a small amount each pay.

BTAA has been endorsed by the Australian Taxation Office as a Deductible Gift Recipient.

ABN 97 733 801 179.

BTAA provides written receipts upon request with donations.



Thanks

BTAA would like to thank the John James Foundation, the Canberra Southern Cross Club, the Canberra Hellenic Club, the Canberra Tradesmen's Club, MSD/Merck (formerly Schering-Plough), the family and friends of the late Gina Raditsis of Melbourne and Virginia Perkins for their recent substantial donations to BTAA.

Contact us

All email enquiries are to be sent to enquiries@btaa.org.au

Follow us on

BTAA wants more friends and followers on Facebook

Go to www.facebook.com and search for Brain Tumour Alliance Australia

Note: we offer peer support, not medical advice, and have a Freecall number: 1800 857 221 (available only in Australia and only free from landlines, not mobiles) where you can speak to someone who knows what it is like to travel the brain tumour journey. N.B. the Freecall number is answered on a person's private number. Please inform the person who answers that you are inquiring about BTAA. Please consult your medical practitioner for medical advice. We are unable to offer financial or material support.

Chair: Matt Pitt. Email: chair@btaa.org.au

Secretary: Denis Strangman Email: secretary@btaa.org.au

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