



Alison shows one of her harps to Cara, daughter of BTAA national committee member Mark Dalliston.

Raising awareness - BTAA TV commercial

BTAA would like to thank Daniel Sanguineti Media for developing the story board and the filming and production of a television community announcement to raise awareness of brain tumours in the community, and of the role of BTAA. The commercial was an initiative of MaryAnne Rosier, BTAA committee member. If anyone has links to television networks which could be approached to screen the announcement please contact MaryAnne at: fundraising@btaa.org.au

Brain Tumour Clinical Professional Day for health professionals in Victoria who support patients with brain tumours.

MaryAnne Rosier will represent BTAA at the Brain Tumour Clinical Professional Day for health professionals in Victoria who support patients with brain tumours on August 17, 2012. According to the forum organizer, Kelly Mills, Project Officer at the Austin Hospital, the response to the forum has been fantastic with 120 people registered already from both metropolitan and regional areas across the State. Delegates are mostly from nursing and allied health backgrounds who are keen to improve the supportive care provided to their patients and their families.

Authorised by Matthew D Pitt, Chair, BTAA.

Contact BTAA
PO Box 76, Dickson, ACT 2602

Freecall (free from landlines)
1800 857 221

Email: enquiries@btaa.org.au

GENTLE HARPER

BTAA is very proud to be sponsoring a pilot program that allows Canberra's Alison Ware, of Gentle Harp, to play for brain tumour patients in the ACT. Alison describes herself as a 'harper' and a 'clinical musician', rather than a musical therapist.

Alison has played for brain tumour patients at The Canberra Hospital, Clare Holland House and in patients' homes. Requests are made either by the patient, their family, or the health professionals who are caring for them.

Alison recently played for the ACT brain tumour network in an intimate gathering in the home of one of the BTAA committee members. All present were moved by the beautiful music played by Alison.

For more information or to let BTAA know about any other musical programs available elsewhere in Australia for brain tumour patients please email enquiries@btaa.org.au



BTAA Chair recognised on the phone book

BTAA Chair Matthew Pitt appears on the cover of this year's Canberra White Pages® and Yellow Pages® book.

See <http://www.whitepagescommunity.com.au/covers-program>

2012 CALENDAR

7-9 August - 5th Annual Scientific Meeting. Cooperative Trials Group for Neuro-Oncology. Brisbane. See: www.cogno.org.au

11 August - BTAA Brisbane Forum. Contact Catherine Hindson, National Committee Member, Brain Tumour Alliance Australia: catherine@btaa.org.au

17 August - Brain Tumour Clinical Professional Day for health professionals in Victoria who support patients with brain tumours. The Austin Hospital.

28 October - 3 November International Brain Tumour Awareness Week. Wear a hat for a day for BTAA. Contact fundraising@btaa.org.au

28 October - Touch Football Gala Day. In memory of the late John Maxwell. Kayess Park, Minto, Sydney. Kicks off at 9 a.m. Register now at www.johnmaxwellmemorial.webs.com. Email Steve: s_borgf57@bigpond.net.au Proceeds to Liverpool Brain Tumour Support Group.

28 October - Newro Foundation's 2012 Brain Tumour Awareness 5 kms Walk, New Farm Park, Brisbane. To launch International Brain Tumour Awareness Week. See: www.newrofoundation.com.au

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BTAA Newsletter Winter 2012

Special edition to mark the first BTAA Brisbane Forum

LETTER FROM THE CHAIR

Welcome to this special edition of the Brain Tumour Alliance Australia (BTAA) newsletter, in association with the forthcoming Brisbane Forum, on Saturday 11 August 2012, which will feature visiting US expert Professor Susan M Chang. Thanks to the Roche Company for their educational support of the Brisbane Forum.

I particularly thank BTAA committee member Catherine Hindson for her work in putting together the Brisbane program, with able assistance from Denis Strangman, Secretary of BTAA. Catherine's daughter Renee Hindson will provide the patient perspective at the forum. Also thanks to Jenny Lloyd who has been BTAA's contact in Brisbane to bring the forum together. Jenny has been helping with the forum, whilst supporting her daughter Tess through recent treatment. We are also grateful to Sarah Thompson and the Cancer Council Queensland for their support. More details about the forum are included below.

Members of the BTAA national Committee will be attending the Annual Scientific Meeting of the Cooperative Trials Group for Neuro-Oncology (COGNO) which will precede the Brisbane Forum.

A feature of the Forum program will be a presentation by brain tumour survivor **Renee Hindson**. At 36, Renee was a single mother of two preschoolers, working full-time in a senior management position and studying for a second postgraduate qualification. After a skiing accident knocked her unconscious, a precautionary CT scan identified a mass on her brain.

After two months of differential diagnosis Renee was finally diagnosed with a glioma and following complete resection in October 2010, pathology confirmed Anaplastic Astrocytoma. Renee has now completed her treatment and is working full-time on making sense of her new life. Renee's story was featured on Channel 9's RPA TV show in May

last year with a follow-up segment in June this year.

The Forum will run from 10 a.m. to 2 p.m. and will commence with separate small group meetings for patients/survivors and carers.

During Professor Chang's presentations local oncologist **Dr Po-Ling Inglis** will be on hand to relate Professor Chang's information to the Australian and Queensland contexts. Dr Inglis works at the Royal Brisbane and Women's Hospital, the Prince Charles Hospital, and privately at The Holy Spirit Northside.

Brisbane neurosurgeon **Dr Lindy Jeffree** will take part in a Question and Answer period at the conclusion of the Forum, together with Brain Tumour Care Coordinator **Vivienne Biggs**, and neuro-psychologist **Dr Gail Robinson** PhD from The University of Queensland.

Dr Jeffree will also show a short video clip during the lunch break of an operation using the revolutionary new neurosurgical procedure of identifying tumour cells by using the fluorescent medium 5-ALA. Queensland Doctors are currently seeking official support for this procedure and are among the first neurosurgeons in Australia to use it. Patients who are about to undergo neurosurgery for their brain tumour should consult the FAQ (Frequently Asked Questions) document about 5-ALA (Gliolan) that can be downloaded from the BTAA website.

The Forum will take place in the Auditorium of the Cancer Council Queensland building, 553 Gregory Terrace, Fortitude Valley, on Saturday 11 August.

The BTAA Forum will not have a paediatric component but the Cancer Council will organise its own brain tumour Forum in November with a paediatric stream. (See: <http://www.cancerqld.org.au>)

Special edition
Brisbane Forum July 2012



BRAIN TUMOUR
ALLIANCE AUSTRALIA Inc.

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- Sydney Forum held in March 2012
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- Melbourne Clinical Professional Day
- Diary Dates

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The Brisbane meeting coincides with "Exhibition Week" in Brisbane when traffic can become congested but parking for Forum participants will be available underneath the Cancer Council building. There is no registration fee but bookings are essential, particularly to assist with catering. Bookings can be made online via the BTAA website (www.btaa.org.au) or by phoning BTAA national committee member and Forum coordinator Catherine Hindson (0412 041 245).

Regards

Matt Pitt
Chair
Brain Tumour Alliance Australia Inc



Professor Martin van den Bent and Dr Helen Wheeler answer questions from the packed audience at the Sydney Brain Tumour Forum jointly organised by BTAA and SNOG.

SYDNEY BRAIN TUMOUR FORUM

Brain Tumour Alliance Australia (BTAA) organised a very successful Forum for patients, their carers and families, in Sydney on 8 March this year.

The Forum was organised in conjunction with the Sydney Neuro Oncology Group (SNOG), with catering generously supplied by North Shore Private Hospital. It was attended by 145 people, with participants from NSW, Brisbane, Melbourne and Adelaide, even though it was intended mainly for Sydney residents.

BTAA invested significant funds and effort in ensuring it was a success, with the attendance numbers indicating that it fulfilled a need.

A feature of the program was the provision of small facilitated groups where patients and family could meet separately and discuss their experiences. In post-Forum feedback these group discussions and the evening meal session were strongly welcomed as opportunities to meet with others in a similar situation.

Unfortunately, the organisers of some patient meetings tend to view facilitated small group meetings and presentations by carers and patients/survivors as being "too difficult" to organise but there is an obvious desire for them.

The main speaker was **Professor Martin van den Bent** from the Netherlands who had been brought to Australia to address a meeting organised by the Roche Company and while he tended to be very softly spoken the audience managed to follow most of what he was saying. Professor van den Bent

was supported by oncologist **Dr Helen Wheeler** from the SNOG organisation whose contribution was highly rated in the meeting feedback.

Other speakers were former carer and BTAA national committee member **MaryAnne Rosier** who lost two siblings to brain tumours, BTAA Chair **Matt Pitt** who is a survivor of an astrocytoma, and **Alanah Bailey** who is a brain tumour care coordinator at the Prince of Wales Hospital, Randwick.

All speakers were well received. Many in the audience expressed a wish that they could also have a care coordinator similar to Alanah at their treatment facility. These sentiments and other feedback indicate that this is probably the Number 1 issue for patients and families in Australia.

BTAA arranged for the presentations to be recorded and these have been placed on a DVD which is available on request from BTAA (contact vicechair@btaa.org.au). The recordings are also available on "You Tube", simply by searching for any of the presenters by name or at the following URL <http://www.youtube.com/channel/UCbusb1yDqZGDwbJmG7shjEQ?feature=watch>

Copies of the book "Navigating Through a Strange Land" were on sale at the Forum, as was the book "Into the Light" written by Sydney brain tumour survivor Clint Beattie. Clint's book is available for \$19.95 via a website: <http://www.arkhousepress.com/biography/into-the-light.html>

The Navigating book is available for \$20 direct from BTAA (see our website www.btaa.org.au)



Brisbane oncologist **Dr Po-Ling Inglis** will provide a Queensland and Australian context to Professor Chang's presentations at the Brisbane Brain Tumour Forum (see page 1).



Renee Hindson and one of her children. Renee will speak about a patient perspective of living with a brain tumour at the Brisbane Brain Tumour Forum.



Brain Tumour Alliance Australia (BTAA) is the only national support and advocacy organisation for the brain tumour patient, family and caregiver in Australia.

Wear a hat for one day during **International Brain Tumour Awareness Week** (28 October - 3 November 2012) to raise funds to help support those affected by brain tumours.

Interested in finding out more and how you can receive a 'hat day support' pack?

Email: fundraising@btaa.org.au
Go to our website: www.btaa.org.au
or visit our Facebook Group "Brain Tumour Alliance Australia" and become a friend.



BRAIN TUMOURS AND DRIVING

Fitness to drive for brain tumour patients - a personal experience
By Mark Dallison, BTAA committee member

Reproduced from <http://www.btaa.org.au/Driving.html>

I had a craniotomy and I needed to notify my local licensing authority [3.2.2.1 Duty to report*]. I had symptoms common to brain tumours, such as seizures, and less common, such as hemiparesis (weakness down one side of the body). Not reporting can mean penalties of up to two years not driving with some licensing authorities, including fines.

It required patience and persistence on my part to get my licence back. My first step was getting the required medical approval. My GP signed off the form, I presume after getting the ok from the neurosurgeon [14.2.11 Intracranial surgery*].

I have read an article where a patient lied about their seizures and the police tried to hold the doctor responsible when that patient crashed. Don't be that person - it's not fair to the rest of us.

Once I had my medical form signed I went to the licensing authority. This was a more difficult stage for me than most because of my seizure and disability. I had a seizure before the operation and hemiparesis, weakness down one side of the body, afterwards.

After a couple of meetings, we agreed that I should have a driving test, so I now have my licence back. Due to my not being able to use my leg normally it took some convincing, but at the second meeting I was able to sit in the car and show them that I could operate

CANBERRA AUTHOR DAINERE ANTHONY WRITES ABOUT HER NEW BOOK

Teenage author **Dainere Anthony** with ACT Opposition Leader **Zed Seselja** at the "mini" launch of her new book. Dainere has a medulloblastoma brain tumour. Reproduced from City News

http://citynews.com.au/2012/new-book-from-unstoppable-dainere/img_0230/#comment-7348

"*Theodore and Friends - Theodore is left out* is a children's book written for young children or parents to share with their children. It is about a bear, who goes away for a long time, when

he returns, he is different. The other bears are all a little scared of him and think that he is no longer able to play with them. So poor Theodore is left out whilst the other bears play their many games. There is a happy ending and the book teaches children about acceptance, tolerance, inclusion and understanding. I did base this story on my personal experiences from my journey." - Dainere Anthony

The book costs \$15 through Dainere's parents at santhone@bigpond.net.au

A FATHER'S NOTE TO HIS DAUGHTER

Written after her brain tumour operation, in the week that she was diagnosed with a Grade 3 Astrocytoma.

To Xxxxx,

We want to thank you for:

being the beautiful, intelligent, energetic, positive and caring person you are; bringing so much joy and happiness into the lives of your mother and myself; bringing into our world and raising two beautiful children, Xxxx and Xxxx; and meeting each challenge in recent years with determination, strength, character and humour.

Our wish is for you to:

*plan your future, all of your future, and not be fettered by negativity; inspire your children, your friends, your colleagues and yes, even those who do not know you with your courage, determination and dignity; continue to make a difference in this world; stay positive and not give in to negative, uncaring, selfish and mediocre people; *get back into the work you love. Show them that you have much to offer and that you can excel at your chosen profession; (*has not been possible) take time to watch and listen to the movies and music you love, to smell the flowers, to cook and taste the food you love; continue to raise your beautiful children to your standards and to develop in them a passion for learning and enjoying life; continue to take photos of your children, people, places and activities you love; and give your children a love of music, of study, of play and of their mother.*

We love you always
Mum and Dad

the pedals. My licence has restrictions, such as driving an automatic and using a steering nob. Initially, it looked as though I was going to need to drive a modified car with my left foot. I decided to practice for six months to enable me to pass the test with the right foot.

I have had to stop driving twice. It was felt my mild seizures were due to fatigue and I was not able to drive for 1 month each time [8.3.3 Recurrent seizure*]. It can be at times a frustrating process. A calm head will serve you well. While there is a realistic chance

of you driving, I don't recommend you give up. To their credit, the licensing authorities and AustRoads are making progress to make it simpler for those of us who have lost their licence through medical reasons.

* Assessing Fitness to Drive - <http://www.austroads.com.au/cms/AFTD%20web%20Aug%202006.pdf>
A specific brochure for NSW residents has been produced: Brain Tumours and Driving - A guide for patients and carers" <http://www.nsa.org.au/documents/item/47>