

Brain Tumour Alliance Australia Inc

Annual General Meeting 24 September 2017

Report from the Chair on activities during 2016-17

Committee members during the year 2016-17

- Chair – Catherine Hindson
- Vice Chair – Philip Steele
- Secretary – Patricia Berman
- Assistant Secretary – Susan Pitt
- Treasurer – Pat Wynn.
- Ordinary Committee Members – Rigoula Roussakiss, Janet Micallef, Julia Robertson, Sally Payne (resigned January 2017), Alice Payne, Pam Hubner, Mark Dallison and Mel Tempest

Unelected honorary positions

- Public Officer – Patricia Berman
- Research – Nicola Sheehan
- WA State Coordinator – Diana Andrew
- Advisers – Denis Strangman and Matthew Pitt

Principle activities in 2016 -2017

BTAA has continued to develop our four identified priority areas:

- **SUPPORT** – supporting the needs of all brain tumour patients and carers and their families through our services, resources and programs
- **INFORM** – develop and provide high quality information in a range of formats to empower participation in decisions about treatment and care
- **REPRESENT** – advocating and representing the BTAA community to ensure their voices are heard and for improved care and research
- **CONNECT** - connecting with people and organisations in the brain tumour community

BTAA continues to investigate brain cancer support material, as part of our grant agreement with **Cancer Australia**, awarded in 2016. This support will enable us to develop relevant material on brain tumours, including for people from culturally and Linguistically Diverse backgrounds, led by **Tricia**.

We received Ethics Committee approval to conduct the project Focus Group research from the University of Queensland, with gratitude to **Dr Danette Langbecker** who oversaw the process. Focus groups with patient and carer groups commenced on 1 September. Particular thanks also to **Di Legge**. Also to **Sally Payne, Jonathon Parkinson, Rigoula, Janet, Philip and Susan**.

BTAA has a newly formed Brain Tumour Support Group that meets in Sydney. The group meets on the 1st Friday of the month at **Chris O'Brien Lifehouse** hospital, Camperdown, near RPA. The group is coordinated by **Alice Parsons** and she is supported by **Gerry Tye** and **Steve Newman**

There is live streaming of the guest speakers to Bathurst's daffodil cottage where brain tumour patient and interested personal gather. A huge thank you to our ambassador **Melissa Johnson** for requesting this service and to **Gerry Tye** for making it happen at the Sydney end.

We continue to advocate for **specialised brain tumour care coordinators** in a range of forums.

Provided a strong consumer voice through a submission to the **Senate Select Committee into Funding for Research into Cancers with Low Survival Rates**. BTAA was given the opportunity to appear before the Senate on 8 June 2017.

- Thanks to **Tricia** and **Susan** for developing our submission, **Nicola** for encouraging a large number of individuals to make a submission. Thanks to Nicola, Tricia, Philip and Alice for appearing with me at the Senate. Also to our members Denis, Susan and Billy Williams for their own submissions and appearing before the Senate.

BTAA

- Continues to provide an **1800 Freecall** number for brain tumour patients and caregivers
- Mailed two **newsletters** to more than 15,000 subscribers to mark International Brain Tumour Awareness Week 2016 and Brain Cancer Action Week 2017.
- Emailed our **e-news** to more than 1,500 subscribers.
 - Mailchimp tells us that around 36% are opened – a high rate.
- Managed the **BTAA Facebook page** with over 2,768 Likes, and monitored social media and google news.
- Assisted with the attendance of **Dr Mary Lovely** at COGNO and hosted the **4th National Summit of brain tumour support groups** in Sydney during COGNO's 2016 ASM.
- Represented the brain tumour community at **AMC review** of the Royal Australasian College of Surgeons, along with **Rare Cancer Forum, Garvan Genomic Cancer Medicine Program, Cancer Voices Australia, and Palliative Care Australia Forum**.
- Worked with the **NSW Oncology Group** and **Cancer Council NSW** and in Victoria the **Austin, Cure Brain Cancer Foundation** to conduct patient/carers forums during **Brain Cancer Action Week** May 2017.
- Auspiced the **ACT Brain Tumour Support Network** meetings each month led by **Philip**.
- Continued with **television community service announcements** around Australia.
- Provided **Educational Grants** to Registered Nurses, Allied Health Professionals and Researchers involved with patients with brain tumours, led by **Catherine**.
- Was again supported by significant fundraising donations from the **Van Zwan Accounting Plus team, the Nicola Scott Educational Support Grant, Engineers Australia, Mel Goes Grey in May, Mel Tempest** and a range of others. We are very grateful for every donation.

The BTAA finances for the 2016-17 financial year	Revenue	Expenses	Net operating balance
2016-17	\$97,180	\$59,228	\$246,435NB

NB The above operating balance includes the grant of \$85K received from Cancer Australia for the Supporting People with Cancer and the \$75K committed by BTAA to produce new information resources for brain tumour patients including those from culturally and Linguistically Diverse backgrounds. This money is to be spent over the period 2015-16 to 2018-19 with major expenditure in the years 2017-18 and 2018-19.