

## Chair's Annual Report on 2017-18 BTAA activities

- Chair – Catherine Hindson
- Vice Chair – Philip Steel
- Secretary – Patricia Berman
- Assistant Secretary – Susan Pitt
- Treasurer – Pat Wyn
- Ordinary Committee Members – Janet Micallef, Julia Robertson, Pam Hubner, Stephen Newman, Alice Parsons and Billy Williams.

### Unelected honorary positions

- Public Officer – Patricia Berman
- Newsletter/e-news editor – Philip Steel
- WA State Coordinator – Diana Andrew
- Advisers – Denis Strangman AM and Matthew Pitt
- Research and review - Mark Dalliston

### Principal activities in 2017-18

In November 2018, BTAA reviewed its four priority pillars at a 2 day Committee meeting, namely

- SUPPORT – supporting all brain tumour patients and carers and their families
- COMMUNICATION – communicating the messages of BTAA to patients and carers
- CONNECTION – connecting to like-minded groups
- REPRESENTATION – advocating and representing the BTAA community

### Principle activities of BTAA during FY 2017-18

#### SUPPORTING

- Provision of a 1800 Freecall number for brain tumour patients and caregivers to call and receive peer-to-peer advice and support. The Freecall service is provided by trained support volunteers, led by Catherine Hindson and Janet Micallef. There were 192 calls to the 1800 847 221 number in the past 12 months, with an average of 16 calls per month. The busiest day was Friday and the busiest months were August and September 2017 and May 2018. The service cost for call hosting was \$999.37. I would like to thank the trained support volunteers who provide hours of their time to enable this service.
- In 2017/18, BTAA posted 201 packages of support materials to patients, their families and carers. Patients can request these resources at no cost through the BTAA website. I would like to thank all BTAA members for their assistance in funding the postage of the packages each year via their membership fees.
- New resources for brain tumour patients are being developed by BTAA following the receipt of funding from Cancer Australia in 2016. BTAA received its grant in 2016 – funding over 3 years from Cancer Australia - to develop brain tumour support material for people from Culturally and Linguistically Diverse (CALD) communities. Tricia Berman is leading this project and it is due to be formally launched in the 2018/19 financial year.

In 2017-18, the two proposed new resources were circulated and discussed through consultative meetings with patients and carers in Brisbane, Sydney and Melbourne in August and September 2017. Following revision of the two resources, they were provided to Polaron for translation into various languages and to do design work. Polaron is also testing the translations with cultural groups to ensure their appropriateness. The two new resources will be launched before March 2019 and made available on the BTAA website.

One resource is called 'It's Okay to Ask' provides a series of questions for patients to consider asking their surgeon or other health professional following diagnosis of a brain tumour.

The second resource is titled 'Your Brain Tumour Pathway' which provides an outline of the brain tumour journey for your doctor/surgeon/health professional to complete with information relevant to your specific brain tumour diagnosis and treatments. Both resources will be available in 10 languages.

## INFORMATION

- BTAA Newsletters were mailed out to 1,500 subscribers in September 2017 to mark International Brain Tumour Awareness Week 2015, and in May 2018 to mark Brain Cancer Action Week 2016. Thank you to Philip Steel and Mark Dalliston for the production of the Newsletters.
- E-News has been emailed to more than 2,100 subscribers since May 2018 as BTAA is now producing a monthly E-News. BTAA has been watching the interest and uptake of each E-News. Particular thanks to Steve Newman who has been producing the monthly E-News.
- Monitoring of social media and google news – thank you to Philip Steel and Susan Pitt who have managed BTAA social media.

## CONNECTING

- BTAA attended and gave a presentation to the third world summit of Brain Tumour Patient Advocates in London in October 2017.
- As occurs each year, BTAA attended the annual COGNO conference held in Melbourne in October 2017. BTAA also held a Patient Forum the day before the conference which was assisted by Dianne Legge who led the discussion.
- Support for patients and nurses to attend brain tumour conference and patient meetings was provided via the BTAA Educational Grant with funds from the Nicola Scott Education Fund.
- BTAA continued its involvement with the NSW Oncology Group with participation in meetings every 2-3 months. Dr Jonathan Parkinson, who chaired the meetings for most of the past FY, is a member of the BTAA Steering Committee for the development of new resources with funds from Cancer Australia.
- In Brain Cancer Action Month – May 2018 – BTAA assisted patients to register and attend forums. The NSW Neuro oncology Group (NSWOG) hosted the Brain Cancer Action Month Patient forum in Sydney and the Melbourne Patient forum was organised by Dianne Legge at the Olivia Newton-John Cancer Centre. BTAA also attended the Mark Hughes Foundation patient forum in Newcastle held in May 2018.

## REPRESENTING

- The BTAA Executive members attended a range of meetings and patient support groups throughout the year. This included participation in forums organised by pharmaceutical company BMS to develop a range of consumer materials on immune-oncology and on accessing medicines.
- BTAA, through its Executive members, assists the development and conduct of regular Brain Tumour Support meetings, including the ACT Brain Tumour Support group which meets each month in the Southern Cross Club, Yarralumla, and the Sydney Support group which meets each month at the Chris O'Brien Lifehouse, Sydney. A special thank you to Alice Parsons, Stephen Newman, Pat Wynn, Billy Williams and Denis Strangman for assisting to lead these meetings.

## **BTAA Finances 2017/18**

The BTAA finances for the 2017-18 financial year were revenue of \$98,878.27 and expenses of \$89,294.85.

Note, in 2016, BTAA obtained a three year grant totalling \$85K from Cancer Australia for the Supporting People with Cancer Initiative – *Producing Culturally and Linguistically Diverse (CALD) Resources* over the period 2015-16 to 2018-19.

## **Minutes of the BTAA Annual General Meeting**

**5:00pm 20 September 2018**

### **SHOUT Office ACT**

**Attendance in person:** Catherine Hindson, Denis Strangman, William Williams, Philip Steel, Susan Pitt and Patricia Berman.

Apologies. Alice Parsons, Pam Hubner, Stephen Newman, Janet Micallef and Pat Wynn.

**Item 1 Minutes of previous Meeting:** Read and moved as a true and correct record.

Moved: Tricia Berman

Seconded: Philip Steel

**Item 2 Chair Report** (as tabled)

Moved: Catherine Hindson

Seconded Denis Strangman

**Item 3 Treasurer's Report:** The treasurer's report has been audited and approved, as tabled.

Moved: Patricia Berman

Seconded: Catherine Hindson

**Item 4 Election of Officers for 2018:**

**Returning officer:** Denis Strangman.

Chairperson: one Nomination                      Catherine Hindson      elected

Vice chairperson: one nomination:              Philip Steel              elected

Secretary: one nomination                      Patricia Berman              elected

Assistant Secretary: one nomination              Billy Williams              elected

Treasurer: one nomination                      Pat Wynn              elected

**Ordinary Committee members:**

The following were elected: Alice Parsons (NSW), Janet Micallef (Vic), Pam Hubner (Qld), Michael Parsons (NSW) and Stephen Newman (NSW).

Meeting closed: 6:00 pm

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