

Lest we forget...

Brain Tumour Alliance Australia observes both Brain Cancer Action Week in May and International Brain Tumour Awareness Week in October

Matthew Pitt, Chair of Brain Tumour Alliance Australia (BTAA)

FOR those living with a serious disease – and few are more serious than brain tumours – every day is marked by its challenges. It would be nice if the burden was only felt during the commemorative day, the week, or even the month which is set aside for specifically raising awareness of the challenges of brain tumours.

On the other end of the extreme is the rest of the public, most of whom have had little to no close experience of a serious illness. For them, special days, weeks and months for various diseases, conditions, and other adversities float past in a continuous stream, and keeping up with them feels an impossible task.

So, it could be argued that neither segment is benefitting from these annual occasions.

But on the other hand, one of the longest-standing special annual occasions - Remembrance Day which is observed to recall the end of hostilities of World War I on that date in 1918 - is the 11th hour, of the 11th day, of the 11th month.

The words for that remembrance include those from Laurence Binyon's Poem, 'For the Fallen':

*They shall grow not old, as we that are left
grow old:
Age shall not weary them, nor the years
condemn.
At the going down of the sun and in the
morning
We will remember them."*

This is not to equate the terrible sacrifice made by soldiers in war to the involuntary suffering of people with serious diseases. Instead, it is to highlight that faced with



Above: The Brain Tumour Alliance Australia 2014 Summit. The 27 persons in the photo represent over 12 Australian organisations working to support people with brain tumours - patients, carers and advocates.

otherwise incomprehensible loss, a time honoured tradition is to take a dedicated time to actively remember and reflect on what exactly was lost, and why.

In Australia these two special weeks allow the brain tumour and general community to place particular emphasis on: 'Why does it have to be so?'

Personally, during these special weeks I think of all those individuals whose words have stirred me over the years and who have since passed away. I think of their struggle, their passion for advocacy, and the insensibility of their loss. Why did they have to pass away? What did they tell all those who listened? What would they say if they were still here today? Why was their disease incurable, while each day medical science advances in leaps and bounds for other conditions?

I picture a parallel universe or two, where all those who lost their lives to serious diseases were instead provided with effective treatments, and go on to live well into old age.

These annual awareness-raising occasions bind together those left behind, those living

with the disease, and those with an interest in the question: 'Why does it have to be so?' It emboldens this cohort to be more strident in advocacy, to know they're not alone, and to not feel shy in discussing their experiences or their activities to improve treatment options and other services.

On that note, it is worth remembering the Second National Brain Tumour Alliance Australia Summit, held during International Brain Tumour Awareness Week 2014, where consumer advocates contributed ideas on how to advance research and support. We are working towards a national plan.

The top suggestions at the summit were:

Prevention

- more general practitioner (GP) awareness

Diagnosis

- earlier access to GPs and MRIs
- three-month follow-up (post-diagnosis) for clarification/understanding
- brain cancer sniffer dogs (Why not! Sniffer dogs exist for melanoma.)

Treatment

- every child to have access to a clinical trial
- fast track drugs (targeted therapies) to the Australian Pharmaceutical Benefits Scheme (PBS reimbursed treatments)

Support and care

- neuro-oncology care coordinators for every patient
- age-appropriate rehabilitation and care

Research

- more money for globally co-ordinated research
- Australian involvement in globally coordinated clinical trials

Research enablers

- patient database for researchers (across all parameters)
- public awareness of brain cancer issues

Other

- more promotion/awareness /advertising
- high profile representation
- single national flag bearer



Above: On a break at the BTAA Summit - Matt Pitt (left), chair of BTAA with Robert De Rose (Isabella and Marcus Foundation).

The most-widely supported top priorities were care coordinators and more money for globally coordinated research.

BTAA believes brain tumour care coordinators make a huge difference to patients and their families - providing support through treatment decisions and other areas. We continue to advocate for more funding so everyone has access to these services.

While BTAA is not able to fund these positions, BTAA provides educational grants to enable allied health professionals to attend professional development/training events within Australia and internationally, with assistance from the Nicola Scott Educational Trust. ■

Attendees at the 2014 Brain Tumour Alliance Australia (BTAA) Summit included representatives from groups around Australia: BTAA, Blackwood 8, Grey Matters, the ACT Brain Tumour Support Network, the James Crofts Hope Foundation, the United Brain Tumour Support Group, the Brisbane Brain Tumour support group, the Cure Starts Now, the Cure Brain Cancer Foundation, the Peace of Mind Foundation, the Robert Connor Dawes Fund, the PNet Cancer Foundation, the Cancer Council Victoria and Brainlink. Several more groups sent apologies but are keen to participate in the next Summit.

about these support organisations can be found on our web site www.btaa.org.au

Sadly, author and active patient and research advocate Sally White from Blackwood 8 was unable to attend the summit due to ill-health. Sally passed away in January 2015. Her legacy will inspire us all to do more for advocacy and to savor each day as survivors.

Rain didn't dampen walkers' spirits

DAE Smith wrote to us to tell us about the Head for the Cure 5K run/walk which was held in April 2015 in Omaha, USA.

She said: "This was our second annual event in Omaha. Our 5K events are great days of celebration for those going through this disease, or for families of those that have passed.

We raise money for brain cancer research and always try and raise awareness around this disease as well.

We had 549 people sign up and even with the rain we still had a great turnout and great energy for this cause!

The total distance walked during the Head for the Cure event was 1250 km which was kindly donated to the IBTA's Walk Around the World for Brain Tumours.

A whopping \$35,000 (USD) was raised for brain tumour research! ■



Above and right: Some of the participants in the Omaha Head for the Cure event

