

Dear Friends,

Welcome to this second edition of the newsletter for 2015.



Anne M. Miller,
*Volunteer Editor,
Brain Tumour
Support Service
Newsletter.*

I must begin by introducing our new coordinator for the Brain Tumour Support Service, Dominique Longshaw, who is working full time for Cancer Council Queensland. You can read more about Dominique on page 3. I hope she will be very happy in her work here.

We have some interesting reading for you in the newsletter. We've included a summary of a talk that Professor Wainwright gave at a thank you morning tea for fundraisers in March. He spoke about the most common brain tumours affecting children. According to Professor Wainwright, current treatments often give the children side effects which can be difficult to manage, so he is investigating new drugs in a series of clinical trials. Cancer Council Queensland is funding some of this research for the next two years; a very valuable and worthwhile use of donations.

An article from Cancer Council Victoria offers advice on coping with behavioural and personality changes. Managing these can be very difficult and frustrating for both the person with a brain tumour and the carer. There are also some great tips for helping people cope with communication problems.

We have an update on Dianne McGinn's fundraiser 'Footprints', which was held on 3 May 2015. Over 360 people participated in a walk to raise awareness of brain cancer and raised a phenomenal \$16,000 for the Cancer Council Queensland's work in brain cancer research and support programs. A magnificent result Dianne! Very well done.

If you would like to make a contribution, visit **footprintsforbraincancer.com**

We have a new website for the Brisbane-based Brain Tumour Support Group! You can visit for **btsg.org.au** updates on monthly meetings dates and times. Do please look it up as it will be very useful.

'Till next time stay happy, keep well and keep smiling.

Anne
Volunteer Editor
Brain Tumour Support Service Newsletter

Thought for the day:

Start by doing what's necessary; then do what's possible; and suddenly you are doing the impossible.

Francis of Assisi

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Brain Tumour Information Sessions 2015 Brisbane

September

Date: Thursday, September 3rd

Time: 10:00am – 11:30am

Topic: **Communicating news about brain tumour to family and friends: What do I say? – presented by Lee Cubis, Griffith University**

Venue: Cancer Council Queensland

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November

Date: Thursday, November 5th

Time: 10:00am – 11:30am

Topic: **It's Okay To Ask – presented by Danette Langbecker**

Venue: Cancer Council Queensland

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New BTSG website

The Brisbane-based Brain Tumour Support Group has launched its new website. The website features updates on meetings, future meeting dates and times, current news regarding treatments and calendar of events.

Visit the website at btsg.org.au

About the Brain Tumour Support Service

Information, referral and support to people who have a benign or malignant brain tumour, their families and friends.

The service provides:

- Information about brain tumours and treatments
- Referral to support and rehabilitation services as well as Cancer Council Queensland's practical support program.
- Regular meetings that provide opportunities to meet other people dealing with a brain tumour and hear health professionals discuss topics of interest
- Regular newsletters offering up-to-date information, stories and support.

Get in touch!

Call us on 13 11 20

Email us at askanurse@cancerqld.org.au

Visit us at cancerqld.org.au

13 11 20

Call 13 11 20 for cancer and brain tumour support information, emotional and practical support. Our cancer support advisors can also refer you to Cancer Council Queensland support programs and other community services.

This free and confidential service is available Monday to Friday 8am–6pm (excluding public holidays) and is provided thanks to the generous donations and support of Queenslanders.

Donate now

Your donations help fund our research and support services for Queenslanders affected by brain cancer and benign brain tumours, including provision of the Brain Tumour Support Service.

Donate online at cancerqld.org.au or call our Donor Hotline **1300 66 39 36**

Welcome Dominique Longshaw

Hello!

I have been at Cancer Council Queensland now for four months.

I have a dual role – coordinating the Brain Tumour Support Service and also facilitating the Support and Information Programs we deliver to people affected by all cancer types, their families and friends.

I have been working in cancer care as a nurse since 1996, and mainly caring for adults undergoing chemotherapy treatments. My work has allowed me to work in Darwin, Brisbane and overseas in the UK, all of which I have found very rewarding as one of my passions is working with people from other cultural backgrounds (being a migrant from Seychelles myself).

I hope to bring my passion for cancer care in my role on the BTSS and I hope you all get a little something out of each edition of our newsletter. I gladly welcome your feedback as to how we can improve our service to you.



Call **13 11 20** or email btss@cancerqld.org.au for more details.

BTAA Summit and Consumer Forum

The Brain Tumour Alliance Australia (BTAA) is holding their third National Summit at the Cancer Council Queensland head office on Thursday 22 October 2015. BTSS will be facilitating the consumer forum.

The interactive forum will take place from 12pm – 3pm, and includes a complimentary lunch with a presentation by Professor Martin van den Bent, a brain tumour specialist from the Netherlands. Professor van den Bent will also be presenting an update on emerging treatments for primary brain tumours at the Cooperative Trials Group for Neuro-Oncology (COGNO) conference that follows the BTAA summit.

After lunch, a panel of guest speakers will provide an update on research and supportive care, including time for questions. This session is open to all with an interest in brain tumours. For further details about this event and to register visit btaa.org.au/events

For more information about 8th COGNO Annual Scientific Meeting 23 – 24 October, 2015 go to cogno.org



Professor Wainwright talks brain tumour research at fundraiser morning tea

On Wednesday 25 March, Cancer Council Queensland hosted a morning tea to thank our fundraisers for their efforts in Australia's Biggest Morning Tea.

Professor Brandon Wainwright, Director and Laboratory Head at the Institute for Molecular Bioscience (IMB) was invited to speak about his research into the genetic programming of brain tumour cells that cause medulloblastoma. The research is partially funded by Cancer Council Queensland.

Medulloblastoma is the most common brain tumour in children. Professor Wainwright said that although research and medicine has made progress in treating childhood leukaemias, "few strides have been made in treating this most common cause of death and disease-related deaths" in children.

Current treatment for medulloblastoma usually involves surgery followed by radiotherapy and then rounds of chemotherapy. However, many children experience late effects relating to the side effects of those treatments.

Professor Wainwright's team have made great progress in understanding the genetic pathways behind medulloblastoma. The team found that there are four types of medulloblastoma, and identified the core genetic features of each. This discovery will enable Wainwright's team to develop treatments that target specific types of medulloblastomas.

As a result of the research, two new drugs are currently in clinical trials:

1. Saridegib or IPI-926, which blocks a chemical pathway necessary for promoting tumour growth, and
2. Palbociclib or PD-0332991, which prevents tumour cell division by stopping a chemical process necessary for genetic material replication.

The development of new drugs from start up to market may take up to 15 years and may cost around \$2 billion.

Professor Wainwright's research is funded by Cancer Council Queensland for the next two years – which is very worthwhile use of valuable donations.



Caring for someone who has a brain tumour

Coping with behavioural and personality changes

Depending on where in the brain the tumour located, a person's behaviour and personality may be affected. Effects from the tumour may include confusion, short temper, forgetfulness, anxiety, depression, sadness and, rarely, aggression. They may become more or less emotional than usual and may become quite withdrawn. People may show behaviour change during the course of treatment. Anger, frustration, anxiety and depressed mood may emerge as they grow aware of their condition. Their senses may also be affected: vision, taste and smell.

As a support person or carer, the following strategies may be helpful to manage these changes:

- Talk to your doctor about any changes you see in the person you are caring for. Your doctor will help you to better understand what is going on.
- Reduce demands made on them without taking away their independence and control. Too many demands or too much stimulation can add to confusion and frustration.
- Try to set achievable goals, limitations and boundaries.
- Try not to take angry outbursts and words personally – try to remain calm.
- Gently remind the person of the changes/limitations that have occurred and why they might need help.
- Be reassuring and encourage them about how well they are doing.
- Use written daily schedules to create routine.
- Keep family members informed of any changes, which will help reduce confusion, tension or potential embarrassment.
- Encourage physical activity as an outlet.
- Don't pretend to know what another person is feeling – ask them.
- If the person becomes agitated about something, try to redirect their attention to another topic. Come back to it later when they are calmer and try to see if you can work out what the concern was and how you might avoid it again.

Tips for communication problems

A brain tumour may affect talking, reading, writing, concentrating and remembering. A speech pathologist and/or occupational therapist at the hospital or community health centre can provide support and advice.

Here are some general tips that may be helpful:

- Talk in short, clear sentences.
- Talk about one thing at a time. Fatigue and memory loss can make it difficult to consider several things at once.
- Allow the person time to respond. Avoid rushing the person or finishing their sentences.
- Check to see if they have understood you. Rephrase or simplify your point if needed.
- Encourage communication, even if it is slow, and maintain eye contact.
- Acknowledge difficulties if the person is getting upset or frustrated.

More information and support

Remember, you can only care for a person well if you also care for yourself. It can be helpful to identify and discuss your thoughts, feelings and needs with the person you are caring for and with others.

Please phone **13 11 20** for further information and support.

Information adapted with permission from Cancer Council Victoria **cancervic.org.au**

Footprints for brain cancer

On 3 May 2015, more than 380 Brisbane locals came together at the annual Footprints for Brain Cancer in a show of strength for Queenslanders affected by the disease.

Footprints for Brain Cancer was founded by Ashgrove local Dianne McGinn in 2012 to raise awareness of Brain Cancer Action Week (3–9 May 2015).

The walk raised a phenomenal \$16,000 for Cancer Council Queensland's work in brain cancer research and support. The event was a huge success and it was encouraging to see such a strong turnout of supporters. It was a wonderful morning for all involved, with sausage sizzles, live music, face painting and fun activities for the kids.

Dianne knows first-hand the need for more research, and ultimately a cure; she was diagnosed with an aggressive grade IV Glioblastoma Multiforme (GBM) brain tumour in 2012. Currently there is no cure for GBM and re-occurrences are completely unpredictable. Recently Dianne's tumour returned for the second time.

Dianne is a busy mother-of-two and although she is currently undergoing treatment, she put in a great deal of time and effort to grow the event this year and support others affected.

Donations to Cancer Council Queensland help provide the Brain Tumour Support Service and fund brain cancer research projects via the Cancer Research Centre. In 2014 the Cancer Council Queensland invested \$800,000 into funding four brain cancer research projects:

- Prof Brandon Wainwright, University of Queensland – A synthetic lethal-based approach for the treatment of medulloblastoma.
- Dr Bryan Day, QIMR Berghofer Medical Research Institute – Understanding the function of salinomycin as a DNA-damaging agent and its relevance as a potential therapeutic agent for the treatment of malignant brain tumours.
- Assoc Prof Greig de Zubicaray, University of Queensland – A prospective study of language function following surgical resection of left hemisphere primary brain tumours.
- A/Prof Jennifer Martin, University of Queensland – Targeting existing therapies with innovative technology platforms to improve survival in brain cancer.

To Dianne, the organisers, and all who attended – we express our heartfelt thanks.

You can take action by donating to Footprints for Brain Cancer at footprintsforbraincancer.com.au





Further information and support can be provided at
any Cancer Council Queensland office throughout
Queensland or by calling 13 11 20.

cancerqld.org.au