



TERRY KENNERLEY AWARD

Tashina Janus – 2019 Terry Kennerley Award recipient

By Rosemary Cashman, Nurse Practitioner

This award is named in honour of a brain tumour patient who became a beloved figure in the brain tumour community. Terry offered support in countless ways to other patients and families and became an outspoken advocate for his community. His grateful admirers included patients, families, health care professionals and even pharmaceutical industry representatives. Terry inspired us all to live life fully with grace, courage and humour, and to think beyond ourselves.

The Terry Kennerley Award honours a British Columbian who has made a meaningful contribution to the brain tumour community. Examples of a meaningful contribution include enhancing patient care; educating patients and/or health professionals; supporting brain tumour research; and raising public awareness of brain tumours.

This year's award goes to Tashina Janus. Diagnosed with a brain tumour at age 21, Tashina found a way to raise awareness



The Hamburger Hockey League with 2019 Terry Kennerley Award recipient, Tashina Janus.

about brain tumours even as she was undergoing treatment. Her work supporting autistic children helped instill a sense of responsibility to those living with health challenges and this inspired her to help others living with brain tumours. Tashina and the Delta Police Department organized a marathon swim (12 hours, unaided, by an intrepid police constable) while Tashina spoke with various dignitaries including a Member of Parliament, The Mayor of Delta, the Delta Police and Fire Chiefs, Police Board Members and various other community figures. This event brought together many different people and Tashina met with cancer patients and survivors. She spoke bravely and honestly with various news and television networks, discussing the importance of self-care, advocacy and hopefulness. Her message of solidarity has crossed international borders and prompted important conversations about care.

It was a sincere privilege to honour Tashina on May 13, 2019.

For more information about the Terry Kennerley Award and past recipients see: www.bccancer.bc.ca/health-info/types-of-cancer/brain-central-nervous-system/terry-kennerley-award#About--Terry



Monica, Tashina and Soraya Janus



Tashina Janus (centre) with previous award recipients Paul Chapman (left) and Margaret Ng (right)

American Society of Clinical Oncology update from Chicago

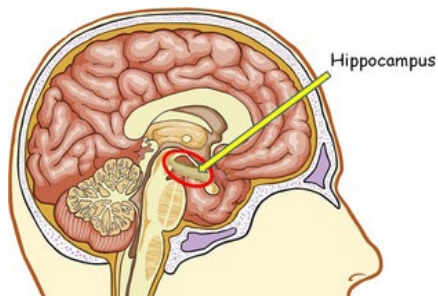
By Dr. Brian Thiessen, Neurooncologist

THE AMERICAN SOCIETY OF CLINICAL ONCOLOGY (ASCO) is the world's largest cancer

conference and offers updates on important cancer research across all cancer types. While there was no impactful new treatment for brain tumours announced, I did learn a number of things during the course of the conference. Some of the things I learned are:

It is really important to avoid giving radiation to the hippocampus.

The hippocampus is a small structure deep in the brain that is the key to encoding and storing memories. Radiation to the hippocampus can damage stem cells in this area and cause memory impairment.



In a pivotal study, patients with brain metastases requiring whole brain radiotherapy (WBRT) were randomized to receive standard whole brain treatment or to receive hippocampal avoidance whole brain radiotherapy or HA-WBRT. It turns out HA-WBRT was as effective as standard WBRT at controlling brain tumors, but cognitive function and quality of life were better with the HA-WBRT. HA-WBRT is being lauded as the new standard technique for patients needing whole brain radiotherapy.

The timing of radiotherapy after surgery for glioblastoma isn't as crucial as we once believed. With a database of over 30,000 glioblastoma patients, time from surgery to radiotherapy was compared to overall survival. As it turns out, only patients receiving radiotherapy within the first 3 weeks after surgery were found to have an increased risk of death. Patients treated with radiotherapy 4-8 weeks after



surgery had no increased risk of death and even patients treated after 8 weeks had only a very minor increase in mortality. So the "Goldilocks" time frame for starting radiotherapy after surgery is 4-8 weeks and something every center should strive for.

Isocitrate dehydrogenase (IDH) is a critical molecular biomarker in glioma. While we always knew it was a diagnostic and prognostic marker, it also has important predictive value in determining which patients should receive

chemotherapy with radiation in grade 2 and 3 gliomas. The RTOG 98-02 trial researchers comparing radiotherapy alone vs. radiotherapy + chemotherapy in high risk grade 2 gliomas presented their molecular analysis. They found 3 distinct molecular groups: 1) IDH mutant and 1p/19q co-deleted (oligodendroglioma group); 2) IDH mutant and 1p/19q intact (astrocytoma group) and 3) IDH wild type (non-mutated). Chemotherapy was profoundly effective at reducing mortality in both IDH mutant groups but had virtually no effect on IDH wild type tumours. Similarly, an updated interim report from the CATNON trial was presented looking at IDH subtypes. This study looked at radiation vs. radiation + chemotherapy in grade 3 gliomas that were not 1p/19q co-deleted (i.e. the astrocytoma group). The molecular analysis divided the groups into IDH mutant and IDH wild type. Like the RTOG trial, the CATNON trial found the IDH mutant patients had best survival with radiotherapy and chemotherapy. IDH wild type patients received no benefit from chemotherapy. Because of these results, all IDH mutant tumours should have chemotherapy as part of their treatment plan to optimize outcomes.

When it comes to temozolomide chemotherapy, more is not always better. The CATNON trial was designed to look at giving chemotherapy either during radiotherapy or after. As it turns out, giving temozolomide after radiotherapy has the most effect in reducing mortality from grade 3 IDH mutant astrocytoma.

However, the benefit of temozolomide with radiotherapy in these patients is small, and the modest improvement in survival from the concurrent treatment will need to be examined in relation to potentially increased late cognitive effects. Another trial looking at how much temozolomide to give was a randomized phase 2 trial from Spain, which studied the use of 6 cycles vs 12 cycles of temozolomide after radiotherapy in glioblastoma patients. They showed there is no difference in survival with the longer temozolomide treatment and 3 times as much significant toxicity. So at least for glioblastoma patients, 6 cycles of temozolomide clearly leads to maximum benefit.

We still have a long way to go with immunotherapy in brain tumours. Various trials using viral therapies, immune checkpoint inhibitors and vaccine therapies all showed minimal activity. Clearly these treatments are not powerful enough to control glioblastoma by themselves. Work needs to be done to see if rational combinations of these therapies can improve the immune system's attack on brain tumours.

Not all targeted therapies are futile in brain tumours. Over the last decade we've seen little activity from agents that target the most frequently altered pathways in glioblastoma. However, there are some malignant gliomas that harbour a genetic alteration called NTRK fusion. Although rare (<5% of gliomas), when identified, tumours with NTRK fusions can respond to an agent called larotrectinib. Response rates were about 36% which may not sound impressive, but typically in this patient population, response rates tend to be under 5%. Clearly this agent is active and suggests that we should increase testing for these NTRK fusions, especially in younger glioma patients.

So in conclusion, a lot was learned at this year's conference. I think a major take home message is that, while we do a lot of molecular testing, we likely need to be doing more to improve how we classify our patients so we can better personalize their treatments.

The Ride to Conquer Cancer— early years of the Brainiacs



Year One RTCC, Jim Vanderhook (centre front), Paul Chapman (second from left) and Yaron Butterfield (third from left)

By Paul Chapman

Back in October 2008, four members of the Brain Tumour Support Group - Jim, Yaron, Jay and I – got talking about the rocky road we had traveled and the fact that we were all doing pretty well after our treatment. We decided we wanted to do something to help cancer research efforts.

I was very much in favour of this idea and asked what we could do. Jim told us about a new initiative of the BC Cancer Foundation to raise funds for cancer research—The Ride to Conquer Cancer. The inaugural event would be on Father's Day in June, 2009, a bike ride from Vancouver to Seattle. I told Jim to put me down for 10 km as I assumed it would be some kind of a relay. He smiled and stated that it's not a relay; we each had to ride 250 km!

I told him this was impossible and he responded, "You just got over a glioblastoma. Nothing is impossible!" After a moment of contemplation, I said "Touché, let's start training when the snow clears." We all agreed and decided to name our team the Brainiacs. And so the four of us from the support group invited four friends to join us and suddenly we had a team, a team name and a ride date. That year we raised \$34,000 for cancer research.

On that first year of the ride, we all gathered at the starting line, ready for our big adventure. I remember feeling so small and insignificant. Teams around us had customized their own ride gear and had large signs held up to signal where

to meet. I vowed to myself we would create our own jerseys for the following year. I met someone who told me what an Ambassador for the Ride was—someone who led a team of 8 or more and raised over \$10,000. I realized – hey, that's me! He also told me that cancer survivors have yellow flags attached to their bikes. Half way through the ride, we managed to get the flag attached to our bikes.

For the second year of the ride in 2010, we each decided to invite another friend to double the team to 16. We also needed to brand ourselves. As an artist, Yaron Butterfield took the challenge head on and created the uniforms for that second year. The bright colours of our cycling gear conveyed feelings of resilience, happiness and strength – a perfect description of our team.



Early days of the Brainiacs, including Jim Vanderhook (centre front), Paul Chapman (behind Jim) and Yaron Butterfield with his twin brother, far right.

After a few years of floating around 30 people, David Desrochers asked us if he could be the team recruitment captain in 2013. Soon after, David asked if I was available to tell my story to 100 new Brainiacs. I reminded David that there was a fair amount of administrative work to be done with this many riders. He told me not to worry, he'd take care of it – and went on to sign up another 100 riders! That year, we went from 30 to 230 riders recruited. On the morning of that ride, I no longer felt small or insignificant. There were Brainiacs everywhere at camp and at the finish line. That year we raised \$595,000 and were awarded the highest fundraising team!

The team has continued to remain relevant and has a small chapter in Ontario and a larger chapter in Calgary. Over these 10 years the Brainiacs have raised over \$2.5 million for Cancer Research!

Each Brainiac has a story and every story is truly inspiring. It has been such a great adventure and privilege to be part of this amazing team.

If you would like more information about the Ride to Conquer Cancer or the Brainiacs, or if you are interested in joining us on August 24-25, 2019 as we ride to Hope, BC, see: <http://www.bccancer.bc.ca/about/events/ride-to-conquer-cancer> https://secure.conquercancer.ca/site/TR/Ride/Vancouver2019?team_id=81793&pg=team&fr_id=1712



Dilek Cansin and her husband, Volker

By Dilek Cansin

AFTER A COURAGEOUS BATTLE with glioblastoma for years, my beloved husband, Volker, passed away last December. I knew it would be a healing experience for me to make use of all I had learned as a care-giver to help other patients and families living with a brain tumour diagnosis. When I was asked if I might be interested in becoming involved in the BC Cancer Brain Tumour Patient and Family Advisory Council (PFAC), I eagerly joined in.

What is PFAC? Founded in 2010, this group of brain tumour survivors and family caregivers meets regularly with BC Cancer staff to bring expert guidance to the care program, develop research initiatives and create a greater sense of community among patients and their families. Joining PFAC has given me a voice to help improve the care of patients dealing with brain tumours and fill gaps in care for family caregivers.

Always very grateful for the excellent medical and supportive cancer care available to us, Volker and I attended the monthly brain tumour support group meetings beginning soon after his diagnosis. We also scheduled counselling sessions with our brilliant social worker, made a list of our questions for our doctor and reached out to our nurse practitioner whenever we had concerns between appointments.

Despite the thorough doctor's appointments, notes and emails, I felt almost as overwhelmed as my husband. The learning curve seemed so steep and there was so much to remember: how to recognize and monitor symptoms and side effects of radiotherapy and different kinds of chemotherapy, what to do in case of a seizure, how to communicate with family and friends, how to keep track of medications and how to care for myself.

In the last few months I have been on the council, PFAC has developed written resources for caregivers to address all these issues. How I wish I had that information in writing, all in one place when I was so distraught and struggling to trouble-shoot!

Over the past nine years, PFAC has also developed:

- Patient Information Days
- Art Shows www.bccancer.bc.ca/health-info/types-of-cancer/brain-central-nervous-system/art-show
- A Peer Navigator Program
- A quarterly patient newsletter, *Headlines* www.bccancer.bc.ca/health-info/types-of-cancer/brain-central-nervous-system/headlines
- The Terry Kennerley Award for outstanding contributions to the brain tumour community www.bccancer.bc.ca/health-info/types-of-cancer/

[brain-central-nervous-system/terry-kennerley-award](http://www.bccancer.bc.ca/brain-central-nervous-system/terry-kennerley-award)

- Written material for those undergoing treatment or interested in Advance Care Planning
- Patient/caregiver participation in clinical trial and grant review committees

For me, lending my talents and expertise to help others rewards me with a healthier and more fulfilling life. Serving on PFAC has certainly helped me move forward through my grieving process. It is such a gift to help empower patients and their families to live as well and as long as possible.

Thanks to our exceptional medical team, Volker and I lived our best life throughout his illness. Now my hope is to use my experience as a caregiver to help others live their best lives even as they face the challenges of a brain tumour.

Do you have ideas about how care could be improved at BC Cancer? Do you have other suggestions for PFAC? Or for more information about PFAC, please reach out to Rosemary Cashman at 604 877 6072 or rcashman@bccancer.bc.ca

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For more information about how you can support enhanced patient care, patient information and brain tumour research, please contact Fatima Hassam, Associate Vice President, BC Cancer Foundation.

Dir: 604 877 6226 Cell: 604 218 0508 fatima.hassam@bccancer.bc.ca

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If you would like to submit an article, ask a question, or serve on our patient and family editorial board, please contact Rosemary Cashman at rcashman@bccancer.bc.ca or 604 877 6072 (phone) 604 877 6180 (fax).