

Headlines

Fall 17

A newsletter for brain tumour patients and their families

TERRY KENNERLEY 2017 AWARD

Ashley Sehmer

THE TERRY KENNERLEY AWARD was initiated in Terry's memory in 2013 by his friends on the "Hamburger Hockey League" and by members of the Patient and Family Advisory Council of the BC Cancer Agency brain tumour program. Terry was diagnosed with a brain tumour in 2006 and passed away in 2010. Throughout that time he charmed his many friends in the brain tumour community through his kindness, his advocacy efforts and his wicked sense of humour. He brought patients to support group; he met with them outside the cancer centre; he encouraged and supported them. He spoke publicly to health care professionals about how to speak truthfully to patients without destroying their sense of hope, and many of these professionals still mention the profound impact that Terry had on their approach to patients and patient care.

This year we honour Ashley Sehmer, diagnosed in 2016 with a brain tumour during pregnancy. Her pregnancy had to be terminated so that she could undergo urgent treatment. To make matters worse, she and her husband had lost a close friend to a brain tumour five months before Ashley's diagnosis.

From the very beginning, and even while undergoing treatment,

Ashley has been determined to "turn a negative into a positive." She has raised

over \$60,000 for brain cancer research and equipment through her creative fundraising events, and has increased awareness about the effects of brain tumours through her presence on social media. This month, she will tell her story in a "Grand Rounds" lecture to physicians at the BC Women's Hospital so that they can learn from her experience. Here is Ashley's story in her own words: <http://donate.bccancerfoundation.com/site/PageNavigator/AshleySehmer.html>

Her award was presented by the 2015 recipient Margaret Ng and the 2013 recipient Paul Chapman.

We all extend our warmest congratulations and thanks to Ashley for her tremendous efforts to help all brain tumour patients.

For more information about the Terry Kennerley Award, see *Headlines* Fall 2013 and Fall 2015.



Ashley Sehmer with the Hamburger Hockey League



(Left to right) Paul Chapman, Linda Knox, Margaret Ng, Joseph Tesoro, Ben Sehmer, Ashley Sehmer



Goal: \$75,000.00 | Raised: \$61,262.00

It is important to me to raise awareness for brain cancer. I was diagnosed with a brain tumour in December, 2016. At the time, I was a normal, healthy 33 year old woman, newly married and pregnant. Brain cancer does not discriminate. It can affect anyone, at any stage in life. We lost our dear friend, James Yang, in July of 2016, to a similar type of brain tumour.

I have decided to tell my story with the hopes of ending brain cancer. Currently there is no cure for the type of tumour that I have, but that does not mean that I have given up hope.

I am fortunate to be receiving treatment at the BC Cancer Agency. Funds raised will go towards new equipment and research. A pyrosequencer will allow the neuro-oncology team to conduct testing for brain tumour patients, so the most effective treatment for each individual can be found. A portion of funds will also go towards BC Cancer's Personalized Onco-Genomics (POG) Program. This is the first program of its kind to deploy whole genome analysis to inform individual treatment planning for patients. With your help we can take the next step in beating brain cancer.



Peer Navigator Program for patients and caregivers

By Tracy Stonehouse, MSW, RSW

WE ARE PLEASED TO BE ABLE TO offer a "Peer Navigator Program" for patients and their family caregivers in our brain tumour care program.

The program was instituted a few years ago to allow a new patient to meet with a "veteran" patient, that is, a patient who has already received treatment for his or her tumour and has also been trained to provide support to a newly diagnosed patient.

This program has been well received by new and veteran patients alike, and an article about its benefits was published in the Canadian Oncology Nursing Journal in 2016 by Douglas Ozier and Rosemary Cashman.



www.canadianoncologynursingjournal.com/index.php/conj/rt/prINTERfriendly/661/0

This year we have expanded the program to include the option for a family caregiver of a newly diagnosed patient to meet with a trained "veteran" caregiver.

If you have recently been diagnosed with a malignant brain tumour and would like to meet with a patient who has been through treatment for this disease OR if you have a family member who

has recently been diagnosed with a malignant brain tumour and would like to meet with another family caregiver with similar experience, this program is for you.

You will meet at the BC Cancer Agency in a private session with the trained volunteer. During this session, you can ask questions and get some "insider information" about what to expect on the road ahead. The volunteer navigators have been through an educational program so that they can conduct these meetings with care and sensitivity.

For more information or to schedule a meeting with a patient or caregiver navigator, please contact:

*Tracy Stonehouse 604 877 6000 x 2814
tracy.stonehouse@bccancer.bc.ca or*

*Rosemary Cashman 604 877 6072
rcashman@bccancer.bc.ca or*

*Patient and Family Counselling
Department at BC Cancer Agency,
Vancouver 604 877 6000 x 2194*

Join the Movement Conference – Brain Tumour Foundation of Canada

BRAIN TUMOUR FOUNDATION OF CANADA is working to achieve its vision to find the cause of and a cure for brain tumours, while improving the quality of life for those affected. The Join the Movement to End Brain Tumours National Conference is an opportunity to hear how we are working towards that vision. It is also an opportunity to connect with the Canadian brain tumour community.

The 2017 National Conference will take place in two sites and two languages this year.

Toronto, October 20, 2017
at Sheraton Toronto Airport Hotel & Conference Centre,
801 Dixon Rd.

A Research Symposium will occur on the afternoon of October 20 and a Celebration Dinner will occur that evening. The dinner will honour our volunteers and celebrate our 35th Anniversary. The conference will continue throughout the next day, October 21.

Montreal, October 28, 2017
at the Hôtel Universel, 5000 rue Sherbrooke E.

Note: this event will be in French and will take place from 8:30 am to 12 noon.



To see the conference agendas, visit:

<http://www.braintumour.ca/5693/national-conference-agenda>

To register, visit:

<http://www.braintumour.ca/5694/national-conference-registration>

or contact: Janic Gorayeb jgorayeb@braintumour.ca

1-800-265-5106 or 519-642-7755 ext 233

Living with seizures

SEIZURES ARE A COMMON side effect of brain tumours, and are the first sign of disease in about one third of people who are diagnosed with a brain tumour. You will remain at risk for seizures throughout your life if you have a brain tumour, but some people never have one. Seizures may also occur in people who do not have brain tumours.

What is a seizure? The cells of the brain communicate through electrical signals. When this communication between cells is interrupted because of the presence of abnormal tissue, including tumour cells, blood or scar tissue, a seizure may occur. If the abnormal electrical impulse is confined to a small, focussed area of the brain, a **focal seizure** results. The experience of a focal seizure is determined by the area of the brain affected. It could be a strange sensation, such as numbness; involuntary movements; odd smells or tastes; or some alteration in consciousness. If a focal seizure spreads over a larger portion of the brain, a **generalized seizure** may occur. Generalized seizures typically result in loss of consciousness, loss of bowel and bladder control, and uncontrollable jerks and spasms. Sometimes people experience a warning, termed an aura, that a seizure is about to occur. This might be a strange taste, smell, or other unusual sensation, including a feeling of *déjà vu*. Because the seizure is due to an abnormal electrical focus within the brain, it tends to occur in the same way every time for each individual.

Can seizures be prevented? The best way to prevent seizures is to take seizure medications (also called antiepileptics). All of these medications can cause drowsiness and dizziness. Your doctor will help you determine the best drug and best dose to control your seizures with the least side effects possible. It is sometimes difficult to prevent seizures completely, but by taking seizure medications, the risk of generalized seizures is significantly reduced.

Special cautions related to seizure medicines include the following:

- The appearance of a **rash** after beginning a new seizure medicine is a serious event that should be reported immediately.
- Seizure medicines should **never be discontinued abruptly**. Sudden withdrawal from these medicines or forgetting to take doses can result in seizures.

What other factors may promote seizures? Certain predisposing factors act as triggers to make a person particularly at risk for seizures, even if they are taking their medicines correctly. These triggers include:

- fatigue.
- poor sleep.
- emotional stress.
- alcohol.
- menstruation.
- fever.

Remember that seizure medicines interact with a number of other medications, including antibiotics, birth control pills and antacids and that this may alter the effects of the medications. Let your health care team know about the medicines you are taking so that they can advise you about the potential for drug interactions.

Can I live a normal life if I am prone to seizures? With some sensible modifications in lifestyle, most people carry on with their normal lives, even if they sometimes have seizures. Protect yourself from situations that are potentially dangerous if a seizure does occur by:

- Wearing a helmet when cycling, roller blading, skiing, etc.
- Swimming with a buddy.
- Letting family members know if you're taking a bath or shower.
- Following the Ministry of Transportation's guidelines for driving – and letting someone else drive whenever possible, even if you have not had a seizure.

- Exercising good judgment when climbing ladders, using power tools, etc.

What should I do if I witness a seizure? Try to remain calm. Remember that although seizures may be very distressing for the person experiencing them and for those who witness them, most seizures are not harmful in themselves. You should:

- Stay with the person who is seizing so that you can try to prevent injury and provide reassurance.
- Do not try to restrict the person's movements.
- If he/she falls to the floor, cushion the head and turn him/her to the side to allow any secretions to flow out of the mouth (rather than be drawn into the lungs).
- Do not put anything in the person's mouth—especially your hand or fingers!
- Try to record the amount of time the seizure lasts so that you can report this to the health care team.
- Speak gently to the person when the seizure stops. He/she may be disoriented, unable to speak or sleepy for a time after the seizure. More rarely, a person may be temporarily paralysed.
- *If the seizure lasts for more than five minutes, if it stops and starts again, or if there are injuries or other concerns as a result of the seizure go to the nearest emergency room.* Otherwise, simply notify your doctor or nurse by telephone at your earliest convenience.

Examples of seizure medications

- Dilantin (phenytoin)
- Tegretol (carbamazepine)
- Lamictal (lamotrigine)
- Epival (valproic acid)
- Keppra (levetiracetam)
- Frisium (clobazam)

Q I have heard that MGMT testing is very important for treatment of my glioblastoma, but my testing was not done because I'm too young. Don't you need as much information as possible and why is this not done for everyone? Also, I am thinking about sending my tumour specimen for more testing through an organization called Foundation One. Have you heard of this and should I send my tumour for this testing? It is quite costly and I am disappointed that there is no coverage for this. It seems there is no way to have this done in Canada.

A Cancer biomarkers are an important part of cancer care, but every biomarker does not have the same relevance. We can divide biomarkers into 3 types: **diagnostic, prognostic and predictive**. The best biomarkers provide all 3 types of information, but those are rare. A *diagnostic* biomarker helps in defining the precise type of cancer we are dealing with. An example would be 1p/19q chromosome deletion. This genetic abnormality identifies the brain tumour as an oligodendroglioma. A *prognostic* biomarker is a biomarker that suggests how a tumour will behave, for example, that it may grow quickly or slowly, or be more or less responsive to treatment. An example is the MGMT methylation test in glioblastoma. Glioblastomas that show MGMT methylation have a better

Question + answer



prognosis and tend to be more sensitive to treatment. Finally, *predictive* biomarkers are those tests that guide the treatment decision plan for a patient. 1p/19q deletion predicts for better outcome with combined chemotherapy and radiation therapy in oligodendrogliomas. MGMT methylation predicts for better outcome with radiation and chemotherapy in patients over 60 years old with glioblastoma (GBM).

Obviously the most important biomarkers are those that provide diagnostic and predictive information. Prognostic biomarkers provide information, but do not alter treatment plans or change diagnoses and as such are lower priority for funding by the province.

The current brain tumour biomarkers funded in BC are IDH mutation (diagnostic and prognostic), 1p/19q co-deletion (diagnostic, prognostic and predictive) and MGMT methylation in patients over 60 years old with GBM (prognostic and predictive). Since younger patients with glioblastoma can respond to radiation and chemotherapy regardless of MGMT status, it only provides prognostic information in that group of patients. And since the prognosis is not so radically different between younger glioblastoma patients with or without MGMT methylation, the province has declined to fund it at this time.

Regarding Foundation One, this is a test that looks at a number of important cancer

genes in the tumour sample to determine if there are known mutations. Some of these genes are relevant to brain tumours and others are not. The concept is that if mutations are identified, treatments can be targeted against those mutations. The problem is that the targetable mutations in glioblastoma are well known from extensive genome testing in the past. Targeting these mutations has been entirely unsuccessful in numerous clinical trials for a number of reasons. Poor penetration of drugs into the brain tissue is a big issue. An even more important problem is tumour heterogeneity, which means that the tumour's cells are very diverse. A glioblastoma is made up of billions of cells and there are many groups of cells in this tumour that will be genetically very different from other groups. If a targeted therapy only hits 15% of the cells, it won't kill enough cells to make a difference. In fact, even if the targeted therapy hits 99% of the cells, that still leaves millions of cells to keep growing. So while extensive gene testing provides a lot of interesting data about cancer cells and what makes them grow, it hasn't led to successful therapies, especially for glioblastoma. As such, this type of expensive gene testing is not covered by the province. Testing that provides results leading to better outcomes for patients is what we all wish for, and what we work towards, but we are unfortunately still a long way from a "targeted therapy" for glioblastoma.

By Dr. Brian Thiessen,
Neuro-oncologist, Vancouver Centre

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www.bccancer.bc.ca/health-info/types-of-cancer/brain-central-nervous-system/headlines
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).

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