

## NEWS & INFORMATION FOR PATIENTS AND FAMILIES LIVING WITH BRAIN TUMORS

### *“Making a Difference in the Quality of Life of People Living with Brain Tumors”*

PROVIDING INFORMATION ABOUT OUR PROGRESS AT THE BRAIN TRUST AND ACTIVITIES AT THE GERRY & NANCY PENCER BRAIN TUMOR CENTRE, BRAINSCAN IS A GREAT RESOURCE FOR BRAIN TUMOR PATIENTS AND THEIR FAMILIES, DONORS, THE MEDICAL COMMUNITY, LIKE-ORGANIZATIONS, AND VOLUNTEERS ACROSS CANADA AND INTERNATIONALLY



### A MESSAGE FROM THE DIRECTOR **Holly Pencer Bellman, Executive Director**

Our Raise a Little Health event was amazing! On Wednesday, June 3, an intimate but energized crowd of 300 gathered for another off the charts Brain Trust Gala celebrating the incredible work of The Pencer Brain Tumor Centre with an evening that Gerry would have loved. Raise a Little Health featured the Iconic Canadian rock band, Trooper performing their popular anthem *We're here for a good time* (not a long time) which epitomized Gerry's life and became the theme song in his fight against brain cancer. As usual, our incredible patrons came together to net \$575,000 in support of The Pencer Brain Tumor Centre at Princess Margaret Cancer Centre.

The world-class reputation of The Gerry & Nancy Pencer Brain Tumor Centre helps attract first-rate doctors and researchers and provide unprecedented treatment and support to patients and their families. This reputation could never have been earned or upheld without our patrons providing funds to help bring Gerry's dream to reality. We thank them for making the evening a success, and invite you to please remember us throughout the year should you wish to further support The Centre by making a donation or purchasing holiday and tribute cards.

This past November 6th, 2015, the Joe Di Palma Brain Tumor Foundation held their 8th annual Gala in support of The Gerry & Nancy Pencer Brain Tumor Centre. 'Mardi Gras' was a huge success hosting almost 600 guests for drinks, dinner and dancing until the wee hours. A great time was had by all, with guests bidding on amazing auction items and one lucky couple winning an all expenses paid trip to New Orleans. All in all, in excess of \$50,000 was raised- bringing the cumulative net earnings of this amazing Gala to \$500,000 for The Gerry & Nancy Pencer Brain Tumor Centre in memory of Joe. Way to go Peter and team!!!

Our 2015 Head for a Cure Walk was held on Sunday, June 21st with over 230 participants in attendance! This special event, created years ago by our very own Patient and Family Advisory Committee has raised a staggering \$1.5 million in 13 years with an impressive \$90,000 in 2015 alone! All proceeds from this event are used to support The Pencer Centre's outstanding patient programs, educational materials, research and staff, and the list goes on. I am so proud of our patient and family community who demonstrate that working together we can move mountains!!

In honor of Brain Tumor Awareness Month, The Gerry and Nancy Pencer Brain Tumor Centre held their second annual Inner Workings Art Show to highlight and showcase the talent and creativity of those affected by brain tumors. For the show, our beautiful space was transformed into a gallery that included 37 displays by 23 different artists. The show began with an artists' reception on Thursday evening where our own Dave Coules shared a self-composed song, 'The Moment of Forever' which has never before been played for an audience. The beautiful song is a tribute to Dave's beloved son Adam who lost his battle with a brain tumor in 2012. Thanks to all for your amazing contributions to this very special event.



Raise a Little Health Gala, 2015  
Holly Bellman, Nancy Pencer  
& Stacey Cynamon

Thanks to all our supporters and everyone who contributed to this issue and as always, if you have any ideas or suggestions about the newsletter, or you would like to get on our mailing list, or have a story to share, please feel free to contact me by phone or by e-mail at 416-665-1515 or [holly@pencerbraintrust.com](mailto:holly@pencerbraintrust.com).



# Ask The Expert

By Dr. Nadine Richard, Postdoctoral Fellow in Neuropsychology at The Pencer Brain Tumor Centre

**Question:**

**I feel like my thinking abilities are not what they used to be. Are cognitive changes normal for someone living with a brain tumor? Is there anything I can do about them?**

**Answer:**

First, know that you are not alone. Cognitive changes (that is, changes in thinking) are common with any injury or illness that affects the brain, including brain tumors. They may be severe, or subtle – but even mild changes in your thinking skills might affect your life and activities in a meaningful way.

Our brains are like very sophisticated supercomputers – a collection of specialized parts wired together to support an incredible range of abilities: moving our bodies, communicating with one another, creating our behaviors and personality, learning new things, imagining our future, remembering our past, concentrating, organizing, multi-tasking, and just negotiating all of life's activities.

Any of these abilities or others may be affected when someone has a brain tumor, depending on the tumor type and location, the type of treatment, and other factors. Sometimes, cognitive changes will improve with recovery time after treatment. Generally, what is good for your body is good for your brain: quality sleep, a healthy diet and regular exercise can help improve your cognitive functioning at the same time as your physical health, energy and overall well-being. Sometimes, patients experience cognitive problems that are longer lasting, but find their own ways to work around them. For example, someone with memory loss might start using calendars and written notes to remember appointments, shopping lists, or

important conversations. And sometimes, patients should consult a professional for help.

If you have concerns about your thinking abilities, how they might affect your life activities (such as returning to work or school, or managing your family or household responsibilities) and what you can do about them, talk to your doctor or anyone on your care team. If you are a University Health Network (UHN) patient, for example, the team at The Pencer Brain Tumor Centre includes professionals who specialize in assessing and treating cognitive problems. You might benefit from a comprehensive neuropsychological assessment to identify your cognitive strengths and weaknesses and provide recommendations. You might also be eligible to participate in a cognitive rehabilitation study that is currently underway at The Pencer Centre. The treatments in this study provide personalized, 1-on-1 training with a neuropsychologist to help you understand and improve your cognitive abilities.

**If you are a UHN patient, you can ask your neurosurgeon or oncologist to refer you for a neuropsychological assessment at The Pencer Centre. You can also call 416-946-2820 for more information about the cognitive rehabilitation study.**



State-Of-The-Art Care • Physical Rehabilitation • Consultation • Participation in Clinical Trials  
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Advisory Committee • Complementary Therapies • Links to Hospital and Community Support Services  
Patient Information Binder • Art Therapy • Support Group Meetings • Internet Access  
Translational Research • A Calm and Positive Environment for Patients and Families

THE GERRY & NANCY PENCER  
BRAIN TUMOR CENTRE  
MISSION STATEMENT

**TO BE A “CENTRE OF EXCELLENCE” WHICH PROVIDES MULTIDISCIPLINARY CARE, TREATMENT, AND SUPPORT FOR BRAIN TUMOR PATIENTS AND THEIR FAMILIES. TO PROMOTE CLINICAL AND TRANSLATIONAL BRAIN TUMOR RESEARCH.**



# The Power of Small Deeds: The importance of 'showing up' when someone you know has a brain tumor

By Suzanne Heft

There are some words that change your life forever.

- “We’re bankrupt.”
- “I want a divorce.”
- “You’re fired.”
- “I don’t love you anymore.”

And:

**You have a brain tumor, and it’s malignant.**

If you have heard these last words, then you or someone you know and care about has been given a diagnosis that will change their life – and the life of those around them – likely forever.

I know a little bit about all this. At age 44 and a mother of two young children, I was diagnosed with aggressive breast cancer. Two years later, my husband collapsed at work -- a seizure, caused by an inoperable brain tumor. He spent the next year and a half in treatment.

I know more about cancer – and more about living with cancer – than I ever thought possible. As my husband’s primary care-giver for a year and a half, I learned a great deal about what it takes to survive and cope with the life changes that a brain tumor forces.

My husband’s brain tumor changed life overnight: it deprived him of his ability to drive, to earn a living, to read, write, and concentrate for more than a few moments on almost anything. Simple tasks like listening to his iPod or checking voice mail became incredibly

taxing. Having a conversation was like running five miles. Over time, radiation and chemotherapy altered his body and sometimes sapped his energy. His moods and his general state of mind were deeply affected by his brain tumor. And though he remained courageous, determined and deeply loving throughout his ordeal, his daily vitality—as an active 49-year old man—was greatly diminished.

The question I was asked over and over again by my relatives, neighbours and friends throughout my husband’s illness was this: ‘What can I do to help?’ Everyone, from neighbours to nephews to colleagues and cousins, family and friends wanted to help -- but didn’t know how.

Many people struggle with this. So I have made a list of ideas based on my experience and share them here. Some of these ideas are self-evident and some are not. This is not an exhaustive list, but the ideas really matter and do make a difference. If you really want to help someone struggling with a brain tumor diagnosis, then you will find the right way to do it (and repeat it).

**1. Send meals.** Everyone has to eat (three times a day) and meal prep is hard when you’re sick. Store-bought meals are good; home-made is better. There is a great online scheduler for this called Meal Train. <https://www.mealtrain.com/> People sign up and then there are no duplicates. I consider this act of generosity an extraordinary blessing (and in many cultures, it’s a ritual that dates to ancient times.) Feed people who are hurt and sick. There is enormous life-affirming power in this act of kindness.

**2. Send mail.** Yes, honest to goodness, mail. Email, cards, notes, postcards. Any will do. Send a parcel with funny articles, comics, jokes, and newspaper clippings. Use Canada Post to reach out and

remind the patient and his/her family that they are not alone. We have a dear friend who sent my husband a greeting card every week for 8 months, with a silly joke inside each one. It made his day to open those envelopes and know he was so loved. Illness can be isolating. Mail is a universal good – it helps the patient know he/she is ‘still in the world’ when people write or send cards. If you don’t live nearby, it’s even more important to reach out.

**3. Music & books and other treats.** These can be for the tired patient who needs an iPod with playlists for those endless hours of chemo transfusions or hours spent waiting for blood-work. Buy an Apple TV, or a Netflix gift subscription or a boxed set of DVDs. Load up an MP3 player with audio books. Ask your local book club for a list of book recommendations and buy a stash of books or magazines for the whole family to read. (It’s not for nothing they call it a ‘waiting room’ – reading material or entertainment is distracting when your mind is racing with worry!) If they are not film buffs or book readers, there are other treats that will be well-received, like a cosy pair of new slippers, a robe, a soft blanket or throw, a basket of fresh fruit, some assorted teas and a new teapot, a home made cake or healthy muffins, a bird feeder and bag of seed for the garden. The point is to be thoughtful. One friend stopped at my house without telling me and filled my planters with potted geraniums (knowing I had no time to do it myself that summer!). A small infusion of beauty or comfort shows your caring and eases pain.

**4. Gifts of Time.** There are so many tasks and chores that people with brain tumors cannot do – getting winter tires on a car or truck, mowing grass, shovelling snow, carpooling kids to hockey, etc. Offer to take dictation and type notes for them. Suggest you can take their dog to the vet or water their garden. Propose to take their kids to a movie so they can have a day to themselves. Buy a weary full-time caregiver a ticket to a concert or just give them ‘the afternoon off’ so you sit with the patient and his/her spouse or partner has a much-needed rest. Show up and offer a gift of time so that you take this on for the person who is sick and for their family.

**5. Financial help:** It’s hard enough having a life-threatening illness; to add insult to injury, many people with brain tumors become disabled and see their income drastically affected. Many

people living with a brain tumor lose their ability to earn a living when they are sick. And costs can pile high. Home-based care, rehabilitative therapy, occupational therapy or nursing care is not always affordable. Many supports can be accessed through the system of government-funded programs that exist in our country, but sometimes this is not enough. Medications can be costly. Not every drug is covered by insurance. If you feel there is a benefit – or a need – then consider raising funds and soliciting donations to help the person and family involved. They won’t do this for themselves. But if you use online tools someone on their behalf can easily do this for them. <https://www.gofundme.com/> is a great website that can easily be set up to tell the story and 100% of donations are directed to the person/family who needs it. Or failing that, leave an anonymous donation of cash in an envelope in their mailbox, as some angel did for us one day. I will never forget this extraordinary selfless and generous act till the day I die.

**Last, remember to ‘just do it’.**

Don’t ask if they need their medications picked up, meals made, grass mowed or if they need drives to the doctor. They will be shy and politely say ‘no’. Just grab your lawnmower and head over and cut their grass. When you’re at Costco, pick up an extra lasagne and take it over. Don’t ask if they need their driveway shovelled or if their eaves need cleaning. Just do it. It will be as though you are lifting pounds of weight off their shoulders. You cannot cure their disease but you can help lighten their burdens and show them you care.

There is that famous line by Woody Allen: “80% of success in life is just showing up.” It’s true. There is no more important time to ‘show up’ than when someone’s life has been changed by the words “You have a brain tumor”. Show up, and your presence will embody these words: “You’re not alone.”

*Suzanne Heft is a mother of two boys, a professional fundraiser for educational causes and her husband Harold Heft, a distinguished scholar, poet and writer, died in 2015 from brain cancer at the age of 50. He was a patient at The Pencer Brain Tumour Centre at Princess Margaret Cancer Centre.*



**“with the new day comes new strength and new thoughts”**

*Eleanor Roosevelt*



## PFAC Tours the Lab!

By Irona Fraser

Regular readers of BrainScan will likely be familiar with The Patient and Family Advisory Committee (PFAC) of The Pencer Centre. This dynamic group of volunteers consists of patients and family members, as well as several staff from The Centre. PFAC meets on a monthly basis in order to lend a patient and caregiver voice to programs and services at The Pencer Centre, as well as to act as advocates for the entire brain tumor community. We organize the annual Head for A Cure 5K Walk to raise much-needed funds for research and programs for patients. The annual awarding of the Adam Coules Research Grant is one example of how PFAC supports brain tumor research. This year, Dr. Peter Tonge, PhD was one of the recipients of this award, to fund his project: “Epigenetic mapping and modulation of glioma cell states to suppress malignancy”.

During the presentation of his proposed project to PFAC, Dr. Tonge enthusiastically offered to give PFAC a tour of his laboratory, and it didn’t take long for the committee to enthusiastically accept the offer! He very graciously guided the tour himself and proved to be a very good tour guide indeed. The tour lasted a couple of hours, but time seemed to fly by! Dr. Tonge did an impressive job of explaining the things we observed in the lab in scientific and clinical terms that were easy for our group of laypeople to understand. He eagerly and patiently answered all of our questions, no matter how rudimentary they may have been. It gave us a much greater

appreciation for what is involved in strong research and the expense involved.

During the tour we were able to observe where the cancer cells were frozen and stored for future use. Dr. Tonge also demonstrated to us, using a (thankfully!) styrofoam model of a mouse, how cancer cells are injected into the mouse for clinical study. We even all had an opportunity to look through the microscope at slides of cancer cells and blood vessels. It was fascinating!

Dr. Tonge also did a fine job of helping us to have a better appreciation for the costs of research. State-of-the-art lab equipment helps to improve data collection and analyze tissue much more efficiently, but it is also very costly.

At the conclusion of the tour, we all agreed that it was an impressive and educational experience and we are very grateful to Dr. Tonge for providing this once in a lifetime opportunity. As one of our members remarked afterward: “Peter’s knowledge and enthusiasm for his lab’s work is very inspirational and gives us confidence that these bright young minds will ease the pain that these tumors cause to so many patients, families and friends”.

Many thanks to Dr. Tonge for making time in his demanding schedule to host our tour!



**Dr. Warren Mason,**  
 Medical Director, The Gerry & Nancy Pencer Brain Tumor Centre  
 Holder of The Kirchmann Family Chair in Neuro-oncology Research

I would like to take this opportunity to introduce a number of new medical staff at The Pencer Centre. Many of you already know Dr. Catherine Maurice as my fellow. Now that

Dr. Maurice has completed her fellowship she has joined us as a staff neuro-oncologist who will have two clinics at the Centre, one dedicated to the neurologic complications of cancer and the other focusing on the treatment of primary brain tumors. She will also be working in the Gamma Knife Centre and the newly inaugurated multidisciplinary neuro-fibromatosis clinic at UHN. Dr. Maurice will be a clinician-teacher at the University of Toronto and is currently completing her Masters in Education at the University of Dundee. Additionally, I have three new neuro-oncology fellows, Dr. Hao-Wen Sim from Melbourne, Australia, Dr. Craig Harlos from Winnipeg and Dr. Erin Morgan from St. John's. With the increasing patient volumes and complex medical issues we are encountering at the Centre, this additional staff will ensure that we can honor our commitment to outstanding patient care, research and education.

Earlier in November the Society of Neuro-Oncology held its

annual meeting in San Antonio, TX. This meeting brings together basic and clinical researchers in all aspects of neuro-oncology and the most promising developments are presented. While there have been no dramatic break-throughs in the treatment of brain cancer, it is clear that the most promising research is now focusing on manipulating the body's immune system to fight brain cancers. Many promising immunotherapeutic approaches are entering clinical evaluation. We at The Pencer Centre are involved in some of these studies and in 2017 we will be opening clinical trials that use vaccines, viruses and drugs that manipulate the immune system to combat brain cancer. This is very exciting and we are all hopeful that these efforts will produce positive results in the near future.

Finally, I would like to offer a heartfelt congratulations and thank you to the Di Palma family and Peter Bordignon for a very successful 8th and final Di Palma Gala held in Vaughn in November. This herculean effort and their fabulous events have generated in excess of \$500,000 in memory of one of our patients, Joe Di Palma. These funds are essential for our activities and we will remain forever grateful to these wonderful people for this amazing achievement and tribute to Joe.

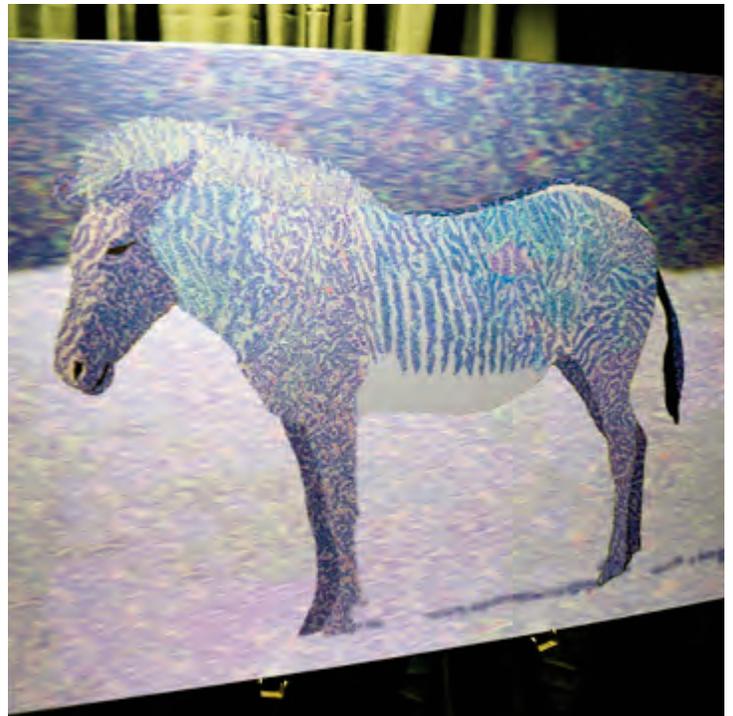
## Inner Workings 2

THE SECOND ANNUAL PENCER CENTRE  
 ART EXHIBITION

By Roger Boyle

In recognition of Brain Tumor Awareness Month, The Gerry and Nancy Pencer Brain Tumor Centre took time to showcase the talent and creativity of those affected by brain tumors, at the second annual Inner Workings Art Show.

The Pencer Centre, located on the top floor of The Princess Margaret Cancer Centre, was transformed into a gallery for the event that included 37 displays by 23 different artists.





The artwork submitted really mirrors the diversity of the brain tumor population," says Maureen Daniels, coordinator, The Gerry and Nancy Pencer Brain Tumor Centre, and Inner Workings founder.

"Brain tumors affect all ages, cultures, and walks of life, and it's evident when you look at the art on display and read each artist's story," she says. "Patients, healthcare providers, friends and family, all participate in the event, and it provides us with the opportunity to come together and share our experiences."

The show began with an artists' reception on Thursday evening, and it marked a moving debut for musician, Dave Coules, who shared a self-composed song, never before played for an audience.

The song, titled 'The Moment of Forever', is reflective of unconditional love and is meant to express the joy surrounding the birth of his son Adam. Dave developed a connection to The



Pencer Brain Tumor Centre when Adam was diagnosed with a brain tumor in December 2006.

Adam passed away on August 31, 2012, and the Coules family has held a strong relationship with the University Health Network (UHN) since.

Also on display was artwork from Dr. Rasmus Kiehl, neuropathologist, Laboratory Medicine Program, who uses microscopic

images to create "compositional microscopy art."

His pieces come together by combining cellular imagery that pathologists see under a microscope in a way that creates new images or recreates existing famous works of art.

Much of Dr. Kiehl's artwork revolves around brain tumors and the science behind identifying and diagnosing abnormalities in the brain.

One of his pieces, called Zebra, uses images taken from a neuropathology consult case of a brain tumor that showed an unusual pattern of "rhythmic palisades." When pathologists encounter an unusual and difficult to classify tumor they sometimes say, "Well, that's a zebra!"

This was Dr. Kiehl's second time participating in the show and he submitted six pieces.

The Inner Workings art show came to be after a Brain Tumor Advocates summit in San Francisco. Speakers shared what they had done to raise awareness for the brain tumor community. Maureen was in attendance and heard about an organization facilitating an art show to fulfill a patients' bucket list wish.

The idea was, "shamelessly stolen," laughs Maureen, and has now snowballed into an annual event for The Pencer Centre.

"One of our patients came up with the name, 'Inner Workings'," says Maureen. "It instantly struck a chord, and highlights the positivity that can be seen from the brain tumor community.

"We have an incredible group of patients, volunteers, and clinicians, and it is wonderful being able to exhibit their talent and creativity."



# Head for a Cure 2015

*By Jesse Varcoe*

On the Saturday before the 2015 Head for a Cure run/walk was taking place, volunteers were gathered in the Princess Margaret parking lot, handing out t-shirts and race packages on what was an absolutely gorgeous day. Even though the wind was blowing (our Head for a Cure sign was thankfully strapped down quite well), many were lamenting just how beautiful it was out, with what was expected to be a much drearier day for the walk the next day...However...

The 13th annual Head of a Cure walk was instead held without rain and in great weather, to the surprise and delight of over 230 participants! Together over \$90,000 was raised for The Pencer Centre in 2015, which is a fantastic achievement. The Head for a Cure walk has raised over \$1.5 million since its inception 13 years ago! All proceeds go directly to supporting The Pencer Centre in the form of programs,

educational materials, research and staff to name a few! We had an excellent turnout, great entertainment both on and off the route, our photogenic firefighting crew, energetic volunteers and a great run/walk route that allowed for participants to really strut their stuff!

A great time was had by all, a new twist on the breakfast sandwich was a big hit, and we are looking forward to building on the success of 2015 with an even bigger showing for our 2016 walk! The Head for a Cure 2016 walk website is already open and ready to accept teams and participants! Sign up early to get a great entrance rate! If you have any questions or need more information on the 2016 event, please feel free to visit the website [www.headforcure.ca](http://www.headforcure.ca) or reach out to Maureen Daniels ([maureen.daniels@uhn.ca](mailto:maureen.daniels@uhn.ca)) or Jesse Varcoe ([jesse.varcoe@td.com](mailto:jesse.varcoe@td.com)).

**JOIN OUR TEAM on JUNE 19, 2016 For HEAD FOR A CURE**  
[www.headforcure.ca](http://www.headforcure.ca)



# International Summit of Brain Tumour Advocates 2015

On October 25-27th 2015, the International Brain Tumor Alliance (IBTA) hosted the second World Summit of Brain Tumor Advocates in Sitges, Spain. Maureen Daniels, Coordinator of The Gerry & Nancy Pencer Brain Tumor Centre was honoured to be invited to participate as a Senior Advisory at this inspiring and innovative meeting. The IBTA World Summit brought together over 70 brain tumor patient advocates from over 20 countries along with experts in the fields of neurosurgery, neurooncology and quality of life research.

The purpose of the Summit was to focus discussion on brain tumor advocacy challenges in the patient organisation environment and to compare and contrast these experiences across the various countries represented at the meeting. The main goal of the Summit was to enable brain tumor advocates from around the globe to share best practice, learn from each other and take back to their own countries innovative approaches to their work.

The meeting programme was 2 jam-packed days of presentations and workshops that touched on a multitude of topics including healthcare systems and regional challenges to accessing therapies, support and information, how to develop and market new brain tumor patient organizations, and fund-raising effectiveness.

Summit participants were privileged to hear Dr. Roger Stupp's presentation on "An overview of current practice and new advances in brain tumor treatments" Dr. Martin Taphoorn's presentation on "Quality of life for brain tumor patients" and Dr. Garth Cruickshank's presentation on "Neurosurgical approaches to brain tumor treatment'. In addition, the group heard very moving and inspiring presentations from a number of participants who described their own successful brain tumor programs, often created from very meagre resources, in countries around the world.

In those 2 short days the Summit served to reinforce a sense of common cause among brain tumor advocates in dealing with one of the most challenging of all cancers. Old friends were able to reconnect and equally important, new friends and contacts were established. All the Summit participants agreed that there was a wealth of helpful, practical information shared and that they would be enthusiastically taking that home their own organisations.

Special thanks needs to be showered on the IBTA's tireless, inspiring Co-Founder, Co-Director and Chair, Kathy Oliver, without whom this meeting would not have come together.





# My Personal Story

By MaryLou Bacci



My journey with cancer started at the end of January, 2014 when I had a Grand Mal seizure in my sleep. I was taken to Emergency for testing and stayed in the hospital for 12 days undergoing several tests. They found a couple of “lesions” on my brain. An MRI showed that one of the lesions was continuously growing, and appeared to be a tumor. At this point, my neurologist referred me to a brain surgeon to schedule a craniotomy for a biopsy of the tumor that was growing.

The biopsy showed that it was a type of brain cancer called “Glioblastoma Multiforme”. I was then referred to an excellent oncologist at Princess Margaret Cancer Centre, Dr. Warren Mason. I had to start chemo and radiation immediately which meant that we were not able to take our family vacation to Italy to celebrate our 25th Anniversary, and both daughters, Danielle and Julia’s, milestone birthdays, 16 and 21. We had to cancel our trip.

At the end of August 2014, 6 weeks after excellent treatment, my blood count was too low to continue with the chemo. In November, my second tumor had grown rapidly and I was in the same position again with surgery. I had my second craniotomy in December,

and followed up with chemo in January 2015. In April 2015, my blood counts were too low again, so I had to stop. At this time, the MRI showed that my original tumor began to grow back and Dr. Mason suggested that I try a different chemo drug called Avastin which stops the blood supply to the tumors.

My first intravenous treatment of Avastin was at the end of May, 2015 and thankfully, I had no side effects. I was to continue this every two weeks. I am happy to say that we took the postponed family trip of a lifetime this summer. We made the most of it and I am so grateful to Dr. Mason, Maureen and all the staff at The Pencer Brain Tumor Centre for their support in making this trip of a lifetime to Italy happen. When I returned back from the trip, the MRI results revealed that my tumor not only stopped growing, but shrunk in size! In addition to the Avastin, I also follow an alkaline diet to keep my body low in acid. I am grateful to my husband, daughters, family and friends for all their love and support. I thank God for bringing me to Princess Margaret Cancer Centre and for all the support I received. I am forever grateful for my life.

## IN MEMORIAM

### Helena Belina, June 25, 1941–August 8, 2015

She was a loving wife, a devoted mother, a medical researcher at the University of Toronto for over 30 years and a tireless, committed friend to The Gerry & Nancy Pencer Brain Tumor Centre. On August 8th, 2015 we were saddened to learn of the passing of our extraordinary friend Helena Belina. Following the loss of her dear husband Branko to a brain tumor 20 years ago, and typical of her generous spirit, Helena wanted to find a way that she could help others who were facing a brain tumor diagnosis. Serendipitously this was at the same time that The Pencer Centre was being created and Helena eagerly became a founding member of our Patient and Family Advisory Committee (PFAC). From the very first PFAC meeting and for the next 17 years she regularly gave her time and energy to any project PFAC took on.



**We are grateful to Helen for her generosity of spirit and time and we will miss her good-natured company and limitless energy. Our sincere condolences to her two wonderful children Michele and Adrian. Rest in peace dear Helena.**



# WHAT'S ON?

Please note that many of the programs offered at The Pencer Centre are on a drop-in basis, allowing people the flexibility to attend when they are able to. On rare occasions, programs may be cancelled on short notice. Therefore, it is always wise to call ahead, to confirm that the program is running on the day you are planning to attend. Please feel free to call Maureen Daniels at 416-946-2240.

**The Gerry & Nancy Pencer Brain Trust** is a not-for-profit organization that was developed by the late Gerry Pencer to make a difference in the quality of life of people who live with brain tumors. This private family foundation is the catalyst in the establishment of The Gerry & Nancy Pencer Brain Tumor Centre at Princess Margaret Hospital, Toronto. The Centre is dedicated to providing multidisciplinary care, treatment, and support for brain tumor patients and their families. Additionally, the Brain Trust, in collaboration with The Brain Tumor Centre will seek to facilitate and fund the best local, national, and international brain tumor research in the hopes of finding a cure for brain cancer.

#### The Board of Advisors of The Gerry & Nancy Pencer Brain Trust include:

- **Dr. Lawrence S. Bloomberg**, Director & Advisor, National Bank of Canada
- **Richard Cole**, President, R.J. Cole Financial Consulting Limited
- **David Cynamon**, CEO, K2Pure Solutions
- **Dianne Lister**, LL.B., CFRE, ROM Governors President and Executive Director
- **Dr. Christopher Paige**, PH.D., Vice President Research, The University Health Network
- **Holly Pencer Bellman**, Executive Director, The Gerry & Nancy Pencer Brain Trust
- **Nancy Pencer**, President, The Gerry & Nancy Pencer Brain Trust
- **Dr. Daniel Silver**, M.D., FRCP (C) Consultant to the Department of Psychiatry, Mount Sinai Hospital
- **Larry Tanenbaum**, Chairman & CEO, Kilmer Van Nostrand Co. Limited

For more information about The Brain Trust contact Janet Babin at 416-665-1515.

#### • Support Groups for Brain Tumor Patients and Families.

Our support groups run the second Tuesday of each month from 7:00 – 8:30 pm. These groups are facilitated by several Pencer Centre staff members. Patients meet as one group while caregivers meet separately in another room. This is a drop-in program and no prior registration is required. Simply come to the Centre on the evening the group meets. The groups provide a wonderful way to gain support by connecting with others who are going through a similar experience. For further information contact Maureen Daniels at 416-946-2240

• **Relaxation Therapy.** The diagnosis of a brain tumor combined with the stresses associated with treatment can often lead to feelings of anxiety. Learn how to “actively” relax by attending one of our drop-in relaxation therapy sessions. This program takes place each Wednesday afternoon from 1:00 pm – 1:45 pm. The program is led by occupational therapist Derry Igoe, and offers patients and family members an opportunity to learn a number of useful techniques for relaxation. This is a drop-in program and no prior registration is required, simply come to the Centre at the above noted time.

• **Head for a Cure 2016 5K Walk:** The earlier you sign up, the lower the registration fee! Head for a Cure 2016 in support of The Pencer Centre will take place on Sunday, June 19, 2016. Online registration at [www.headforacure.ca](http://www.headforacure.ca) is now open. For additional information about the event please contact Maureen Daniels at 416-946-2240.

• **Inner Workings 2016.** Don't miss an opportunity to be part of this special event! We are looking for anyone who is affected by a brain tumor, to share you artistic talents in our Third annual “Inner Workings” art show in October 2016. Dates to be announced. For more information contact Maureen Daniels@ 416-946-2240.

• **Patient Information Binder.** Our Patient Information Binder is as popular as ever. Included in each binder is a copy of “Brainspirations,” a treasury of inspiring stories, poems, and recipes published by our own Patient & Family Advisory Committee (PFAC). If you are a patient of the Pencer Centre

and have not received a copy of our Patient Information Binder please contact Maureen Daniels at 416- 946-2240. This binder is an excellent organizational tool for keeping track of appointments and all the other information you need during your ongoing treatment. It also contains a wealth of information on brain tumors, treatment, available support services, and much, much more. With thanks to Merk Canada, the binder also contains a DVD copy of our educational video “Radiation Therapy and You”. Thanks also to The Brain Tumor Foundation of Canada for providing copies of their invaluable Patient Resource Handbook.

• **CD Rom:** Our highly acclaimed CD-rom, “Understanding Brain Tumours” contains over 20 hours of information on brain tumors, available treatments, supportive care services and even real life patient experiences. This CD is accessible via the computer in the Resource Library of the Pencer Centre. In addition, copies are also available to borrow through the main Patient & Family Library at Princess Margaret Hospital. The staff at The Centre or one of our resource volunteers would be happy to help you learn how to use this wonderful tool. If you would like to book a time to come in please call Maureen, at 416-946-2240 or drop by the Resource Centre.

• **AYA Program:** Are you a young adult (under 40) and diagnosed with a brain tumor. The Adolescent and Young Adult (AYA) program offers support and information that address concerns that are unique to young people. If you would like to be connected to the program, speak to your Pencer Centre Team or contact [aya@uhn.ca](mailto:aya@uhn.ca). For the across Canada program visit [www.ayacancerCanada.wix.com/resources](http://www.ayacancerCanada.wix.com/resources).

## BRAINSCAN

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