

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

Gala 2018 is already in the works! As of now, the wheels are spinning, but our party plans are top secret. Be the first to know all the exciting details as they become available by visiting www.pencerbraintrust.com today and registering (look for the bright green

banner at the very top of our home page and click!). We are so thankful for our ongoing donor community support. It is because of your generosity that doctors and scientists at The Pencer Centre are continuing to make unprecedented strides in discovering new treatment protocols for brain tumor patients, and implementing them worldwide. Our world-class reputation could never have been earned or upheld without our patrons providing funds to help bring Gerry's dream to reality.

Our 2018 Head for a Cure Walk will mark the 15th year of this close-to-our-hearts event and we plan to make it the best one ever! Registration is now open so head to www.headforacure.ca and register today as an individual or a team. There are no limits to what our Patient and Family Advisory Committee can accomplish and this year is sure to be our best one yet! Get

involved today! All proceeds from HFAC are used to support The Pencer Centre's patient programs, educational materials, research and staff, and the list goes on.

I would like to take this opportunity to thank all of our incredible third party fundraisers who continue, even after losing a precious loved one, to support The Gerry and Nancy Pencer Brain Tumor Centre. In our eyes, these individuals are all heroes and work tirelessly to make a difference in the lives of newly diagnosed brain tumor patients and their families. We are so lucky to be the beneficiary of countless fundraising events that are conceived and orchestrated by an army of people who are all part of our Brain Tumor Centre family. Please check page 5 for a full list of upcoming and past events.

THANKS TO ALL OF OUR SUPPORTERS AND EVERYONE WHO CONTRIBUTED TO THIS ISSUE. 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 EMAIL AT 416-665-1515 or holly@pencerbraintrust.com.

DID YOU KNOW?

The Pencer Centre has a toll-free number!

1-877-282-HOPE 4673



Melissa Nichols is the driving force behind the Hats for Hope project

Been There, Done That

By Melissa Nichols

Although I've 'been there, done that and wrote the book', literally, I'm not interested in telling my story again as it doesn't help me. Instead of re-hashing years of chronic pain, tears and frustration, I am the opposite. Unlike denial, I am open about sharing whatever you ask, however I light up when telling you about days after the surgery when I was flirting with the young, good-looking surgeon, high on morphine with a drainage tube sticking out of my head. Or the time when I was in the live-in patient rehab unit and I held my gifted cupcakes ransom-only to share with those I liked; basking in my newfound power. Also, I can share when I was learning to walk again and having 'spurts' of success, to the point where I would sneak up behind family to scare them-the memory still makes me smile. It was suggested perhaps putting a bell around my neck so I would warn them I was coming!

Life before the brain tumour had already prepared me for the harsh yet humbling truths of life. After so many years of working in health-care, paired with personal loss/struggle, I had an idea of what to expect. I learned the harsh truths of how life presents itself. Yes, bad things happen randomly to good people and life can be unfair, but, life can also be amazing. You can either sit around and complain about what happened to you or what you want, or you can be thankful for what you do have and thrive.

Whatever helps you cope, do it! Reach out and make peace within-do whatever works for you to move on. I hope you don't spend the rest of your life wallowing in your own self-pity or holding on to the brain tumor patient or loved-one who 'called off the battle' years ago. You must live, you must find peace-and help not just yourself but those around you who need a friend the most. I will always be your friend.



State-Of-The-Art Care • Physical Rehabilitation Consultation • Participation in Clinical Trials
Social Worker and Psychiatrist • Resource Library • Patient and Family 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.



My Head for a Cure, Journey to Conquer Cancer

by Robert Jesus.



My life was normal, I was 38 yrs old, married with 3 great kids and always busy running from work to the kids soccer games and a myriad of other activities they had on the go. I was always tired, but I thought it was just spending too much time at work and not getting enough rest throughout the week. Until one day I remember being in the garage and having a wrench in my hand and it just dropped right to the floor. This happened a few times that day, so my wife told me to go inside and rest, figuring I was just tired. After a few days at work I still felt off and I decided to drive myself to the nearby hospital and try to explain the way I was feeling. I sat at the hospital for hours and after telling the doctor about my symptoms, they decided to do an MRI, I was worried but I didn't want my wife or family to worry, so I kept it to myself.

All I remember on March 31st, 2012 was being in the room with a doctor telling me I have a brain tumor and thinking- that's it, I am dead! I called my wife and told her to meet me at the hospital and she came right away. When I told her the news, she and I both cried.

Life changed that day for us with a series of doctor appointments, many medications and a whole new language that we were so unfamiliar with. My surgery was done on April 2012 following treatment with medication, radiation and chemo; along with many other appointments at doctors offices and hospitals and follow up MRI'S. Not every appointment was a good one, I would always hope for good news, however that was not always to be. After starting a new drug, hoping this

was my miracle drug and would keep the tumor sleeping, it did just that. My life was different yet again, I had lost most of the feeling in one arm and my foot plus my leg was not functioning as it should. Now I was walking with a cane and a leg brace which made life hard for me, I was not able to do normal everyday things. I was so sad and would sit most days in a chair and not want to do much activity.

One day while at physio, the therapist said to me to enjoy my life and my family and try and make the most of the things I could still do. That stuck in my head and I tried to go for a walk outside, I was only able to walk to my neighbours' driveway and back but I kept going and then would walk to the 2nd neighbours' house and back, I kept trying three times a day until I was able to go to the end of my street and back. My body was hurting as I was using muscles I didn't think I still had. I would sweat and be exhausted after, but I felt accomplished. I knew I wanted to do more and go further and push myself. I invested in a good pair of running shoes and great workout music and as I walked, I secretly started tracking my distance every day.

Life was our new normal again and while visiting PMH, I saw a table set up for the Journey to Conquer Cancer-1,3 or 5km run or walk and I turned to my wife and said, "I am going to do it!". She said okay we can do the 1km with the kids, but I told her my goal was to do the 5km and I was determined to do it. Every day I would walk, even in the cold and rain all along listening to my music with my 5km goal in my mind. I had my heart set on it and only my wife and kids knew I was doing this race. This race had even more meaning to me because it was being held on Father's day. I wanted to do this for my dad who lost his battle with colorectal cancer 5 years prior to me being diagnosed with my brain cancer.

I wanted to do this for everyone I would see at The Pencer Centre, not only the patients, but the doctors, nurses and the staff who have given care and hope to anyone going through this hard life we have.





I was thrilled to have my 3 kids; Lauren 17, Sophia 13 and Mason 7 and my wife Sharon tell me they were walking with me and for me!

Race day was exciting and scary I was ready to do this and knew I could as I had been practicing everyday for months. I started the race with my family beside me and my music in my ears with the hope that I could

accomplish my goal. It was hard but every step closer I took to the finish line was worth it, I felt accomplished that I did it! I still walk almost every day as I want to keep what I have with the hope that I can gain more strength to continue this long journey with my family by my side.

See you all at next years walk.

The Pencer Centre Clinical Trials Department



Mariya Bakalets, Stephanie Baker & Elena Chizov, The Pencer Centre Clinical Trials Coordinators

What does it take to create and run an effective, productive, efficient clinical trials department? The answer is many things. It takes a dedicated and engaged leader to direct the activities of such a department. It takes resources in the form of funding. And when it comes to actually enrolling patients on clinical trials, monitoring their progress as is stipulated by the trial protocol and organizing all of the details related to ongoing participation in a trial, you need people who are devoted to doing all of that meticulous and important work.

Meet Maryia Bakalets, Stephanie Baker and Elena Chizov. These three women are the heart and soul of The Pencer Centre Clinical Trials department! Together these three nurses manage all of the studies going on at The Pencer Centre and represent over 20 years of combined experience working in clinical trials. At the writing of this article, there are 14 clinical trials underway at The Pencer Centre. These are a mixture of Phase 1, 2 & 3 studies. If that sounds like a busy world, it is!

But the demanding pace of a clinical trials program is part of why Mariya, Stephanie and Elena find this work so rewarding. They all agree that working together as a team with great communication and collaboration is one of the aspects of their role that they enjoy very much.

As Mariya explains, “clear, effective communication between all of the study collaborators facilitates efficient ethics approval so that new studies can be opened quickly”. Mariya adds that the busy CNS clinic is a challenging environment to work in, but it is also rewarding to be able to offer additional, novel treatments to patients. Stephanie says that “the opportunity to get to know and follow patients and their families

over a long period of time is also something that I really enjoy about my role”. Elena echoes this sentiment, “our patients seek our assistance for a lot of things while they are on study. Not only is it rewarding to be able to help them, but it fosters the development of enduring relationships”.

While the role of Clinical Trials Coordinator is one with a lot of autonomy of practice, it also involves mountains of paperwork, requires good assessment skills, being highly organized and meticulous attention to details. Mariya, Stephanie and Elena are also quick to point out that their work is supported by an army of other staff, like the pharmacokinetic nurses, the ethics team, data managers and staff of other departments within the hospital, who work behind the scenes on every study, to ensure that all the details are addressed and that things run smoothly for both the patient and the requirements of the trial.

When asked for their thoughts about what patients should know when they are contemplating participation in a clinical trial, they advise that “study eligibility is always a complicated question. It is always best to speak to your healthcare team about what options are available in your specific circumstances”. “Also as a general rule, participation in one study at a time is usually the rule of thumb”.

The clinical trials department at The Pencer Centre is led by Dr. Warren Mason. He observes that “our dedicated clinical trials nurses, ensure that patients enrolled in our studies receive the required tests and treatments in a timely manner and are monitored closely for any potential side-effects. They are an essential part of our clinical trials program”.



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

It has been a few months since my last dispatch and there have been some changes in The Pencer Centre clinical trainees. Firstly, Dr. Erin Morgan has completed her Fellowship at the Centre and has accepted a position in neuro-oncology at the University of Western Ontario. We wish her a long and successful career in London, Ontario. Replacing her are two Fellows that many of you will meet in the next few months—Dr. Navya Kalidindi who has just finished her Residency in Neurology at the University of Ottawa and Dr. Rose Or who has been a practicing Neurologist in Manila, Philippines who is now fulfilling her desire to become a neuro-oncologist. Education is a central mandate of our Centre and we are very pleased with our Fellowship program and proud of its graduates.

As always, our Patient & Family Advisory Committee (PFAC) continues its incredible support of The Centre and this year had another very successful Head For A Cure 5K walk. As of the writing of this column, this year’s event has raised \$100,000 to support a variety of activities at The Pencer Centre. We remain grateful to their ongoing commitment to The Centre, as without them our work would be so much harder.

Finally, in November many of us will be attending the Annual Meeting of the Society of Neuro-Oncology (SNO) in San Francisco. This is the largest gathering of scientists and physicians who focus their work on brain tumours and I do hope to have news of exciting new developments in research and treatment to share with you in my next column.

“You can do ANYTHING, but not EVERYTHING”
 unknown

to benefit **The Pencer Centre**

Fundraising through events is a great way for you, your community and your friends to help us conquer brain cancer. The Gerry & Nancy Pencer Brain Tumor Centre is fortunate to be the beneficiary of a number of fundraising events each year. These events are conceived, organized and carried out by an army of people who have a special place in their hearts for The Pencer Centre. We are so grateful for their hard work, dedication and generosity. Here is a list of Upcoming and Past Events.

UPCOMING EVENTS

June 17, 2018 Journey to Conquer Cancer Run or Walk -
 Head for A Cure www.headforacure.com

PAST EVENTS

- Year round** Adam Coules Tribute
- March 25, 2017** Todd Wonacott Curling Tournament
- May 6, 2017** ‘Squash Dementia’ Tournament
- June 13, 2017** Pickle Barrel Golf Tournament
- June 18, 2017** Head for a Cure
- August 14, 2017** Kathy Morrison Memorial Golf Tournament
- August 26, 2017** Dan’s Backyard BBQ

Ask The Expert

Lian Pablo, Radiation Therapist



Question:

Q: I am just about to start a course of radiation treatment for my brain tumour. Are there things I can do for myself to get through this treatment with as few side-effects as possible?

Answer:

Starting any type of treatment can be intimidating and hearing all the possible side effects from radiation treatment can be even more overwhelming. In preparation for your treatment, we will be talking about fractionated radiation therapy. Other types of radiation treatment such as stereotactic radiosurgery will be discussed in a future column. In addition to your radiation oncologist, radiation therapists are the members of your team you will see most frequently—each time you come for treatment. The radiation therapists you will meet have completed at least one year of university prior to entering a 3-year program earning a joint Bachelor's degree and advanced diploma in Health Sciences. This program includes both didactic and practical training on a clinical rotation that is required before completing a certification exam by the Canadian Association of Medical Radiation Technologists.

On your first day, a radiation therapist will go over the entire procedure and answer any questions or concerns you may have. The entire procedure should take about fifteen minutes or less, and during the treatment, you will not feel anything as the machine rotates around you to deliver the radiation. You will also be wearing a mask which is meant to maintain your head position and keep you from moving during treatment. The mask will feel snug but should not be painful or intolerable for 10–15 minutes. The radiation therapists will do everything they can to ensure you are comfortable prior to leaving the room to administer your treatment, so feel free to let them know if the mask feels too tight or restricting. You will also be seeing familiar faces on your treatment unit, and your regular team of radiation therapists will be looking forward to getting to know and support you throughout the course of your treatment.

Prior to your first day of treatment, your radiation oncologist might have already prescribed you medications such as steroids,

since headaches, nausea and vomiting are some common side effects of the radiation. If you were not prescribed any medications beforehand, you can also try taking what you normally use for nausea (such as over the counter anti-nausea medication) or having it on hand as a precaution. It is important to take your medications as prescribed as they are essential in reducing or eliminating these side effects.

While the amount of hair you will lose during treatment depends on the type of treatment and the dose you will be receiving, there are plenty of ways in which you can be gentler with your hair. For example, reduce the amount of hair products you are using and avoid extremely hot showers. Using a hat or scarf to keep your head covered will also be helpful in protecting your scalp from the sun, as your scalp will always be more sensitive during and after the course of your treatment.

During your treatment, you may also experience fatigue or tiredness. The amount of fatigue a patient experiences, depends on their overall health and varies from person to person. Understanding that your body will need time to recover from treatment, try to pace yourself and your regular day to day activities to allow yourself time to rest or take naps throughout the day. Give yourself enough time to get to and from treatment in order to allow you to move at a comfortable pace to decrease stress and exhaustion from the travel or commute. Getting a good night's rest, staying hydrated, and eating well-balanced meals throughout the day are some of the things you can do to help reduce fatigue over the course of treatment. Remember that going through treatment will be a job on its own so try to delegate difficult tasks you would normally do, in order to conserve your energy as much as you can.



On top of seeing your radiation therapists every day, you will also be seeing your radiation oncologist once a week to make sure that your side effects are under control. Finally, it is important to know that the Radiation Nursing Clinic is available for you on any treatment day of the week (Monday to Friday) if you are experiencing any side effects from treatment that require immediate attention.

If you have other questions or concerns please contact Liane Pablo, Radiation Therapist.

WELCOME BACK STEPHANIE & WELCOME ELIZABETH

I recently returned from maternity leave to my role as clinical trials nurse at the Pencer Centre. I am proud to announce that I have a beautiful daughter Elizabeth who was born April 22, 2016. I was fortunate to have taken an extended maternity leave to spend time with my daughter past her first birthday as she learned to walk and talk. I look forward to seeing her every day when I return home from work.



Green Collard Soup

by Sonia Silva,
Secretary for The Pencer Brain Tumor Centre

INGREDIENTS

- 12 Russet potatoes, peeled, washed and diced
- 1 large onion
- 1 bunch collard greens - rinsed, stemmed and thinly sliced
- 2 tbsp. of olive oil
- Salt to taste
- Vegetable Bouillon Cube
- 1 pound sausage (Chouriço fully cooked mild or spicy, cut into 1/2" thick rounds)

Preparation time: 20 mins
Cooking time: 30 mins
Serves: an army (a small army)
Enjoy with bread and butter

DIRECTIONS

- In a large pot, cook potatoes with onion, bring to a boil, and let it boil gently for 20 minutes, until potatoes are mushy.
- Meanwhile, in a large skillet over medium-low heat, cook sausage until it has released most of its fat, 10 min., drain.
- Mash potatoes or puree the potato mixture with a blender or food processor
- Add 2 tbsp. of olive oil, vegetable bouillon cube and salt
- Stir the sausage into the soup and return to medium heat. Cover and simmer 5 minutes.
- Stir green collard and let it simmer for 5 min. until it's tender.



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 Cancer Centre, 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
- **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 Ilyse Lax, 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.

• **AYA Program:** Are you a young adult (under 40) and diagnosed with a brain tumour. 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. For across Canada program visit www.ayaprincessmargaret.ca

• **Head for a Cure:** Save the Date - June 17, 2018! Be sure and mark Sunday, June 17, 2018 on your calendars for Head for a Cure 2018. For more information or to register visit: www.headforacure.ca

DID YOU KNOW?

The Pencer Centre has a toll-free number!

1-877-282-HOPE4673

BRAINSCAN

BrainScan is published by The Gerry & Nancy Pencer Brain Trust. Inquiries or requests to reprint any of the articles should be directed to Maureen Daniels, Coordinator, The Gerry & Nancy

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