

# BRAINSCAN

## NEWS & INFORMATION FOR

### PATIENTS AND FAMILIES LIVING WITH BRAIN TUMORS

VOLUME 5 · NUMBER 5 · FALL/WINTER 2004

THE GERRY &  
NANCY PENCER  
**BRAIN  
TRUST**



*"Making a Difference  
in the Quality of Life  
of People Living  
with Brain Tumors"*

#### *A Message from the Director*



**Holly Pencer Bellman**  
Executive Director

This past October marked 'Brain Tumor Awareness Month' in Canada, and boy were we busy!

Our second annual 'Head for a Cure' 5K walk, in conjunction with the Toronto Marathon, was an 'over-the-top' success. Over 120 patients, their families and friends participated, and over \$80,000 was raised – almost double the incredible totals from last year! October 17th was a cold, rainy and miserable day but nonetheless, the mood was festive and the camaraderie undeniable! My father Gerry was right there with me as I walked alongside such an inspiring group to raise money for the cause closest to all our hearts. My sincerest thanks to our very own Patient & Family Advisory Committee (PFAC) for raising the bar and, once again, pulling off such a successful event.

October 29th was the date of our 6th Annual Open House and Speaker Series. The

day started off on a high note: The crowd cheered as our very own Irona Fraser was announced as the 2004 recipient of the prestigious 'Guy Morrison Volunteer of the Year Award'. Joanne Morrison, who was married to the late Guy Morrison, presented Irona with her award. Irona, a long-term brain tumor survivor, is a founding member of our Patient & Family Advisory Committee. She has been a wonderful volunteer through the years, and has acted as both a fundraiser and a brain tumor advocate. Congratulations to Irona and her family on this unbelievable honor! The day continued with a terrific talk by the fabulous Karlene Nation. A reporter, writer and diversity producer for CFTO/CTV News in Toronto, Karlene is also a brain tumor survivor, and delivered an inspiring talk about her personal battle with this disease to a 'standing-room-only' crowd.

Following our guest speaker, The Pencer Centre was thrilled to welcome over 250 patients, families and staff to our Annual Open House. As usual, The Centre was overflowing with interactive displays designed to help visitors learn more about living with a brain tumor, as well as illustrate the multitude of treatments, programs and services available at The Pencer Centre. The highlight, no doubt,

*continued on page 3*

*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 the United States.*

## *sparkle*

THURSDAY | JUNE 2 | 2005

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Proceeds will support research and patient care at The Pencer Brain Tumor Centre at Princess Margaret Hospital



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- THE GERRY & NANCY PENCER  
BRAIN TUMOR CENTRE**
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  - Live and Learn Program
  - 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
  - OUR MISSION:**  
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.

Technology gave this year's "Head for a Cure" team a huge boost.

Many members of The Pencer Centre's Patient and Family Advisory Committee set up personal pages on the Head for a Cure website, complete with beautiful photos and heartwarming stories, and invited family and friends to donate online.

The online contribution method meant that sponsors could make a donation and receive a tax receipt almost simultaneously. Of course, old-fashioned cheques and cash were just as welcome.

And the walkers were immensely successful. The approximately 125 participants in October's 5-K walk/run have raised the gargantuan sum of more than \$80,000.

This event, held to coincide with Brain Tumor Awareness Month and the Toronto Marathon, has become an annual fundraiser for PFAC and The Gerry & Nancy Pencer Brain Tumor Centre.

All funds raised by Head for a Cure go into an endowed fund administered on PFAC's behalf by the Princess Margaret Hospital Foundation. The annual accrued

## 2004 HEAD FOR A CURE a **HUGE** success



*Despite the cold and wet weather, Head for a Cure 2004 was a huge success. Thank you all!*



committee, Henriette Breunis, Katherine Bryce, Susanne Capone, Steven Ferrari and Neetu Malik, all the walk participants and the hundreds of donors. A huge thank-you to you all.

Those who are still collecting their pledges are reminded to please submit them to Maureen as soon as possible. 🌻

*by Lois E. Abraham and Henriette Breunis*

interest will be used to fund special projects at The Pencer Centre.

If you have any ideas or suggestions for a project, program or piece of equipment that would benefit patients of The Pencer Centre, PFAC would like to hear from you. Please e-mail your thoughts to Centre Co-ordinator Maureen Daniels at [Maureen.Daniels@uhn.on.ca](mailto:Maureen.Daniels@uhn.on.ca) or give her a call at 416-946-2240.

The Oct. 17th event wouldn't have been such a huge success without the efforts of the Head for a Cure planning

### “quarterly quote”

For myself

**I am an optimist –**

it does not seem to be much use being

**anything else.**

**Sir Winston Churchill**



**Dr. Eng Siew Koh**

Clinical Research Fellow in  
Radiation Oncology

**D**r. Koh completed her undergraduate medical degree at the University of Adelaide, South

Australia then undertook her Radiation Oncology specialist training in Westmead Hospital, Sydney completing in January 2004. She had begun her interest in radiotherapy as a medical student undertaking research into soft tissue sarcomas and then completed a national research project on radiotherapy quality assurance for pediatric brain tumors for which she received a national award.

She counts it a distinct privilege to be the third Clinical Research Fellow since this role was conceived four years ago at the Pencer Centre.

'The Fellowship period is a wonderful season to be able to further develop professional interests, knowledge and skills in specific tumor sites as well as presenting an opportunity to travel and see different parts of the world!'

So why would an Australian pack her bags and travel 15,000 kms to move to Toronto, Canada? The answer, in the eyes of the global cancer community, is that Princess Margaret Hospital is most certainly a centre of international repute and renowned for its vision and leadership in oncology.

'The decision to come to Canada has propelled me into an environment both rich in resource and opportunity to be involved in innovative collaborative research projects and also

to continue a quest for mentorship by clinician scientists who are not merely leaders in their field of expertise but whom also possess truly global vision, influence and impact. I have the privilege of working under the direct supervision of Associate Professor Normand Laperriere and also the outstanding multi-disciplinary team at the Pencer Centre.'

Dr. Koh's Clinical Research Fellowship commenced in July 2004 and is focused on the management of adult brain tumors as well as with childhood cancer, the latter role having strong links with the Sick Kids Hospital. The field of neuro-oncology presents such an exciting and diverse interface with many differing medical specialties in all arenas of health services and is laden with emerging technologies and innovative treatment modalities. It also presents major challenges in the provision of excellent care for patients and their families in a truly holistic way.

'I am constantly amazed, inspired and energized by the incredible courage of my patients and their families in the midst of their significant physical, emotional and spiritual challenges; and this always continues to stir and give me greater passion to strive to provide them with the best care possible.'

Dr. Koh's particular research interests include addressing in the role of functional imaging such as magnetic resonance spectroscopy in its ability to be able to predict patterns of recurrence in glioblastomas, as well as the investigating issues in the management of adolescents and young adult survivors of cancer and their continuing health care after completion

of initial anti-cancer therapies.

'I am also personally passionate about leadership development, and have an interest in international health systems and resources. One of my dreams is to work on a global scale transforming both the health systems of entire nations.'

Although the Australian health care system has significant similarities to Canada, at present Dr. Koh has the opportunity to immerse herself in an environment resourced with state-of-the-art technology for the treatment of brain tumors, such as a dedicated linear accelerator for stereotactic radiotherapy, radiosurgery, as well one of the largest pediatric radiotherapy practices in North America.

'At present I am thoroughly enjoying not only the amazing career opportunities but also the beauty and diversity of Canada as a country! With one proviso – perhaps you should ask me the same question after I've experienced a Canadian Winter!'

Dr. Koh is certain her year spent training at the Princess Margaret Hospital, especially at the Pencer Centre, will be a defining period – professionally and personally, marked by rich personal friendships and the establishment of strong international networks and connections. These may be a potential foundation for future international collaborative studies.

'Perhaps when I return overseas future generations of oncologists such as myself may one day be challenged to emulate and build on the unique vision, spirit and success that is the Pencer Centre.'

Thank you – I am very grateful for this opportunity. 🌸

## Director's Message *from pg 1*

was The Traveling Hat Display, a collection of 85 hats, each one as unique and special as its owner. The display pays tribute to the amazing individuals who have struggled so bravely with a brain tumor.

All in all the event was an incredible success, and visitors left with full stomachs (the food was top-notch thanks to Madelon Cooper and her team) and loot bags jam-packed with lots of great stuff. As always, mere thanks are not enough to express our gratitude to Maureen Daniels and her dedicated team of healthcare professionals and volunteers who

helped make the Open House a truly memorable day.

In other news, the 'Gala Event of the Year' will soon be upon us, so mark your calendars now! 'Sparkle' will take place on Thursday, June 2, 2005 at The Liberty Grand Entertainment Complex, Exhibition Place in Toronto. Prepare to be transported to a glimmering, shimmering world of fun and fantasy! The stunning Governor's Room will be transformed into a sparkling Crystal Palace – a mosaic of crystal, mirrors and candle-light where you'll dine on gourmet fare, dance to your favourite live music of today and yesterday, browse our 'all-new' outdoor market of spectacular silent auction prizes 'under

the stars', and delight in the many surprises along the way. Dress in your favorite "denim and diamonds" as you enjoy a sparkling evening filled with over 1,000 patrons and net proceeds even greater than last year (\$500,000!). To add your name to our invitation list, or to become one of our esteemed corporate sponsors, please contact our 'Sparkle' Hotline at 416-923-2999.

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 if you would like to get on our mailing list, or have a story to share, please call (416-923-2999) or drop me an e-mail at (hollybellman@aol.com). 🌸

2004 RECIPIENT OF THE GUY MORRISON  
**IRONA FRASER**  
 VOLUNTEER OF THE YEAR AWARD

When it comes to volunteers, The Pencer Centre is truly blessed to have a committed and faithful team. From the members of our Patient and Family Advisory Committee (PFAC) to the volunteers who come to The Centre on a weekly basis to assist in our clinics and in other ways. Many of our volunteers have been involved with The Centre since the very beginning. As a result, the yearly selection of the recipient of The Guy Morrison Volunteer of the Year Award is a difficult task for the selection committee!

This year's winner is a lady who could not be more deserving of the honour. Irona Fraser has been a member of The Pencer Centre Patient & Family Advisory Committee since the very first meeting in June 1998. Diagnosed herself with a brain tumor in 1988, she works tirelessly with PFAC. Irona has been one of the driving forces behind the creation of the beautiful quilt at our juice bar, and the dream catcher, which hangs so proudly in our conference room. She is a vocal advocate for people living

with brain tumors and works year round to raise public awareness of the challenges that those individuals face. Her dedication and commitment serve as an inspiration to both other people living with brain tumors, as well as the staff of The Pencer Centre.

Joanne Morrison, Guy's wife, presented Irona with her award at The Pencer Centre Open House on October 29th. Following the presentation, Irona spoke eloquently about being this year's recipient. "I am really overwhelmed to be honored this way. Guy was such an inspiration to all of us. He and Randy, last years' recipient, were really a great team. Thanks to the Pencer family for making Gerry's dream come true, and for me to be a small part of it. I would also like to publicly thank my son Spencer for initially talking me into going to the support group at the Western Hospital. Also to my daughter Nadine, who faithfully drove me to all of the meetings so that she could learn as much as she could about brain tumors, and for also joining PFAC. Last but not least, many thanks to my husband of almost 50 years, Bill. He now drives me to the support group. I thank him for putting up with me and trying to slow me down when I try to do too much. I realize I am lucky to be here after 16 years. This journey has allowed me to meet some wonderful people who I call friends. I will never forget Guy. He is always in my heart."

Congratulations, Irona! We are so grateful for your dedication to The Pencer Centre.

*Each year, the "Guy Morrison Volunteer of the Year Award" honours an outstanding volunteer at The Gerry & Nancy Pencer Brain Tumor Centre and within the brain tumor community. Guy Morrison was a loving husband, father and good friend. Diagnosed with an aggressive brain tumor in November 1997, he never had a "why me" attitude. In true Gerry Pencer fashion, Guy quickly turned his paralyzing fear into positive energy. A founding member of The Patient and Family Advisory Committee, Guy and his wife Joanne helped shape the programs and services at The Pencer Centre, raise awareness about brain tumors, and counsel newly diagnosed patients and families. After a long and arduous fight, Guy succumbed to his brain tumor in March 2002. His passion for helping others will live on in our hearts forever. 🌻*



Left to right: Bill Fraser, granddaughter Melissa Donohue, and Irona Fraser.

In 1995 I was a medical student at the University of Toronto. As part of my surgery rotation I spent two weeks on the Neurosurgery service at the Toronto Western Hospital. During my rotation I saw brain tumor patients with Dr. Mark Bernstein. I found my experience on that rotation very sad. Those short two weeks had a real impact on me as a medical student.

Over the next few years I became a busy family physician in Toronto. I loved what I did and basically worked so that I could travel.

On July 1, 2003, I was driving back from a long weekend in Algonquin Park. Earlier that day, as I lay in the sun on a piece of the Canadian Shield, I remember saying that "life just doesn't get any better than this." I was truly content.

About one hour into the drive home, on Highway 11, I suddenly felt very odd and found that I was turning my head to the right even though I knew that I should be looking at the road. Then my right hand came off the steering wheel and started shaking uncontrollably. I could not put it down. My sister and my friend started to scream "what's wrong" and that's when I found I could not speak either. Then I blacked out.

The next thing I remember was being on the side of the road and trying to move myself to an ambulance stretcher. My sister had somehow been able to take control of the car from the passenger side and steer it across two lanes of traffic to the shoulder. It is a miracle that none of us were hurt. I had experienced a generalized seizure.

I was taken to Soldiers Memorial Hospital in Orillia where the Emergency physician ordered a CT scan. With my sister holding both of my hands, he told me that I had a very large brain tumor. He said to me "I'm sorry - you'll want to prepare." It was all so surreal to me. I had had no prior symptoms - not even a headache.

I was airlifted to the Toronto Western Hospital and on July 3rd I underwent surgery to remove the brain tumor. I was operated on by Dr. Mark Bernstein. A familiar face who also happens to be one of the best brain tumor neurosurgeons in the world. For most of my surgery I was awake. I felt fine afterwards and was discharged the day after my surgery.

After the surgery, Dr. Bernstein came to see me. He told me that he was unable to remove the entire tumor. To



## Hopeful and Optimistic

by Susy Lin

do so would have left me with a significant neurological deficit. He advised me that radiation and chemotherapy would be necessary. It wasn't what I had hoped for but at that point, I will be honest, I was happy to be alive.

An appointment was made for me to see both Dr. Laperriere and Dr. Mason two weeks later at The Pencer Brain Tumor Centre.

On that day I was told that I had a grade III anaplastic astrocytoma. I figured the worst had already happened to me so I was expecting the news. I met Dr. Laperriere and Dr. Mason and plans were made for the radiation and chemotherapy.

After my appointment, I was given a tour of the entire Centre. The place was beautiful and I found there were fresh flowers everywhere! I was given a binder with lots of information. I was no longer a physician in this setting – I was a patient. The information and wonderful stories in the binder were very helpful to me as I was dealing with a diagnosis that only three weeks ago had seemed impossible.

I underwent five weeks of uneventful radiation on the lower levels of PMH. I then started chemotherapy last October. I wasn't sure what to expect or how I would feel with the chemotherapy. To my surprise, the chemotherapy was pills for five days a month and that was it! I never had significant nausea and aside from some fatigue that was totally manageable, I felt fine. The medication was *Temozolomide* and it has made a real difference in patients with brain tumors.

Brain tumors in many ways are different from other cancers. They rarely metastasize. The experience can be different. At the urging of another patient, I decided to attend the Brain Tumor Support Group.

I thought I didn't need the Brain Tumor Support Group but I

am so glad I finally decided to attend. Meeting other people with brain tumors was very helpful. I met

other younger people. I met wonderful older people.

In June 2004 I was in Greece on a cruise. I was on the Internet

reading up on some world news.

On the front web page was an article about a new treatment that had improved the survival time for patients with malignant brain tumors. Clinical advances for patients with brain tumors has been very slow compared to other cancers. In any event this new treatment, major news in the world of oncology, was a combination of *Temozolomide* taken at the same time as radiation. This was big news and when I 'Googled' it there was a flurry of information about it. One of the centres for this landmark study was The Pencer Brain Tumor Centre at the Princess Margaret Hospital.

Already I have seen that most of the newly diagnosed patients in our support group are on this regimen. It makes me feel good to see that the results of a study can be so quickly applied to clinical practice.

Over the last year I have had monthly visits to the Centre to see Dr. Mason. At my last visit in October Dr. Mason and I decided that one year of chemotherapy was enough!

It has now been 16 months since I was diagnosed. In October, I was able to walk in the Head for the Cure 5K to raise money for The Pencer Brain Tumor Centre. If you had told me a year ago that I would be walking a 5K this October I would not have believed it.

I initially believed that it was "game over" for me. That, I have happily found, is not the case! I am now working two to three days a week as a physician, and feel very well. The word "cure" is not used very often in the treatment of brain tumors. Despite that, I feel hopeful and optimistic.

I feel hope because I am a patient of The Pencer Brain Tumor Centre. With these recent clinical advances, researchers can continue to work to improve the lives of brain tumor patients and – ultimately – develop a cure! 🌟



*Susy enjoys the warmth of Istanbul, Turkey during the summer of 2004.*



**Dr. Warren Mason**  
Medical Director

On November 2nd, The Pencer Brain Trust and the Princess Margaret Hospital Foundation hosted a Donor Appreciation Event at The Centre. During the course of the evening, I presented the results of the recently announced glioblastoma study

that has shown improved survival for patients who are treated with early temozolomide chemotherapy and radiotherapy. The Pencer Centre was a major player in this international clinical trial, and many of the patients treated at our facility participated. While positive results are always good news, I also reminded the audience that the study was what we call a phase III trial that involved a group of patients who did not receive the experimental treatment. To this extent, these patients

received no personal benefit from participating in the trial – they agreed to receive radiotherapy alone – the standard of care at the time. I made this point to emphasize how indebted we are to our patients who choose to participate in clinical trials. Participation in a clinical trial is very much an act of altruism, a willingness to subject oneself not only to unproven, usually ineffective and potentially harmful interventions, but also to conventional  
*continued on next page*

## Caregivers Corner



### The Accidental Friends *by Tracey Hoyt*

As caregivers to loved ones living with brain tumors, we have learned the critical importance of taking care of ourselves.

In 2002, a group of us at the caregiver support group at The Pencer Centre became very close as we helped our loved ones and each other through this very difficult disease. Those monthly meetings were lifelines for all of us, as care giving can be such an isolating experience.

Sadly, as time went on, we each lost our loved one. We attended funerals, memorials and celebrations of life. We sat shiva. We grieved together. Our friendships deepened in these very difficult moments.

Without the support of the staff and fellow caregivers at The Pencer Centre, this experience would have been unimaginably lonely and devastating for all of us. Caregiving didn't end when our loved ones died; we needed it more than ever.

In July of 2003, out of a need for

additional bereavement support, we decided to start a new group outside of PMH, at the same time as the caregiver meetings. First we called ourselves *The Pencer Pals* and now we like to refer to ourselves as *The Accidental Friends*. These friendships are blessings to all of us.

We now hold our meetings at each other's homes, helping to deal with the slow process of grief – over great food, wine, conversation, tears and, with more and more frequency, laughter.

We've discovered the healing nature of food – it's clearly meant to be shared. We are nourishing our bodies and our souls with each potluck dish that we prepare, whether it's garlic roast potatoes with rosemary, caviar on fancy crackers, hearty meat dishes, healthy salads full of surprises, refreshing fruit salads or drinks. We are getting more and more creative with every meal and are seriously considering writing a cookbook.

We can't imagine spending the second Tuesday of every month anywhere else.

*One small year  
It's been an eternity  
It's taken all of me  
to get here  
Through this one  
small year.*

Shawn Colvin

Our meetings have recently felt different – there has been a definite shift. We are finally looking forward, making plans and daring to step into this courageous new chapter in our lives.

We strongly encourage other caregiver support group participants to start their own bereavement groups, so that they may be able to prosper from support once they leave the gentle and caring arms of The Pencer Centre and PMH.

July 2004 celebrates our one-year anniversary as a group. We've come a long way and the journey certainly isn't over, but we're clearly in this together, as Accidental Friends. 🌻

Barbara-Ann's

## Mum's Scottish Shortbread

Just in time for the holidays, our own Dr. Barbara-Ann Millar shares her mum's recipe for traditional Scottish Shortbread. Beware... regular consumption could prove addictive!

**1/2 lb plain flour**  
**1/4 lb cornflour**  
**1/4 lb icing sugar**  
**1/2 lb unsalted butter**

Makes enough for 2 x 8" round tins.

- 🌻 Set oven temperature to 150°C/300°F.
- 🌻 Mix butter, icing sugar and gradually add flour and cornflour (beware – icing sugar + cornflour can travel long distances!)
- 🌻 Mixture should form fine breadcrumbs (but variable).
- 🌻 Divide between the two tins
- 🌻 Pat down mixture with back of metal spoon and smooth
- 🌻 Prick all over with fork and edge with fork prongs
- 🌻 Bake for 45 minutes, remove when lightly golden
- 🌻 While warm, divide into 'petticoat tails' in baking tin and dust with caster sugar.
- 🌻 Allow to cool in tin before removing

Enjoy this healthy Scottish eating option!!!



## Addressing use of Complementary and Alternative Medicine (CAM) Therapies in Neuro-Oncology

Complementary and alternative medicine as defined by NCCAM (The National Centre for Complementary and Alternative medicine) is a “group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine.” These may include treatments such as massage therapy, acupuncture, aromatherapy, herbal, and naturopathic therapies.

Complementary therapies are those that are given in conjunction with the cancer treatment prescribed by the oncologist; while alternative therapies are used in place of conventional cancer treatments, for example, dietary modifications instead of chemotherapy, radiation, or surgery.

In recent years, there has been a movement away from traditional medicine preferring alternative therapies for common and chronic conditions such as arthritis, eczema, and chronic fatigue, for example. Recently, this enthusiasm for non-traditional therapies has made its way into the area of treatment for more serious illnesses like cancer.

### Why is it important to talk about this?

Complementary and alternative therapies such as therapeutic touch, relaxation therapy, and massage therapy have all proven themselves to be beneficial, as they do not interfere with traditional treatments for brain tumors. However, there are other alternative therapies such as ‘herbal medicines’ or other ‘supplements’ that when ingested, may interfere with traditional treatments prescribed to brain tumor patients.

### Is there something in particular that is not advisable?

As a rule of thumb, our oncologists advise patients to avoid taking antioxidants (for example vitamins C and E), during the course of radiation treatment, and for one week after completing radiation treatments. Antioxidants interfere with the effectiveness of radiation treatment. The same holds true for chemotherapy...non-traditional herbal supplements should not be taken on the days of chemotherapy and for a few days after chemotherapy has stopped. Their interactions with chemotherapy are unknown. Large or “mega-doses” of minerals and vitamins should also be avoided as they may interfere with proven, traditional medical treatments that are known to be effective.

### Why is your health care team hesitant to endorse naturopathic or herbal medicines?

Your oncologists have spent many years in training to learn about traditional treatments (chemotherapy, radiation, and

surgery), their merits, and drawbacks. They invest a large amount of time on an ongoing basis to update their knowledge with new information that becomes available on treatments that they may be currently prescribing, or new treatments that are being developed. They depend on solid research that is based on large, scientific, multi-centre, randomized, clinical trials. The primary reason for hesitation in promoting or encouraging alternative treatments is that for the most part, there have been no scientific trials conducted in academic settings that can support the safe use of alternative therapies either on their own or in tandem with conventional ones.

### How will we make progress?

“The National Cancer Institute is establishing programs to increase the amount and quality of CAM cancer research, support the production of high-quality CAM cancer information and facilitate the dialogue between CAM practitioners and cancer researchers”. (White JD, 2000).

### What can you do while this research gets underway?

- ☀ Only visit a registered herbalist or naturopath
- ☀ Ensure he or she is well informed about the treatment you have been prescribed at the cancer centre (because this is treatment which under controlled circumstances has shown benefit, and should not be altered in a way that changes the benefits for you)
- ☀ After you have been advised by the naturopath or the herbalist, discuss the proposed alternative treatment with your treating physician before you begin. Your treating physician may be able to advise you to the safest time to take this treatment...before, during, or after stopping your conventional treatments for the tumor.
- ☀ Make your cancer centre pharmacist part of your team. The pharmacist often knows about alerts that may have been raised in relation to a specific agent or medication, and may be able to guide you in making a decision that is in your best interest. The pharmacist can also look for harmful drug interactions that can be avoided if you discuss the ingredients of your non-traditional medicine.
- ☀ Beware of any health care practitioners that tell you they have a treatment that will cure your tumor or put it in remission. These are usually false claims.

*Often herbal medicines are thought of as gentle, with little or no side effects because they are extracted from naturally existing plants. But, you should be aware that some of the most potent and toxic chemotherapy drugs are derived from plant sources! ☀*

## HELPFUL WEBSITES FOR VALID INFORMATION

<http://nccam.nih.gov/> • [www.naturaldatabase.com](http://www.naturaldatabase.com) • <http://cit.cancersource.com/>

## Medical News *continued from page 6*

treatment if randomized to a control group. The hope is that eventually a new treatment will be developed, one that will improve the outlook for those who will be diagnosed in the future. For this reason, I felt it was particularly important to acknowledge patients as those most responsible for making this important trial possible.

I also want to highlight a few important changes in our staff. Dr. Ruxandra Costa, our neurooncology fellow, has left

to pursue independent practice in the state of Oregon. Dr. Costa was with us for over two years, and provided excellent patient care. We wish her well in her future endeavours. Also, we have two new radiation oncologists on staff, Dr. Barbara Ann Millar, who was previously a fellow here, and Dr. Cynthia Menard, who returns to Princess Margaret Hospital after a period at the National Institutes of Health in the United States. Both have a strong interest in the treatment of brain cancer, and I personally look forward to working closely with our new radiation oncologists. ☀



**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 multi-disciplinary 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:**

- **Lawrence S. Bloomberg**, Director & Advisor, National Bank of Canada
- **Richard Cole**, President, R.J. Cole Financial Consulting Limited
- **David Cynamon**, Chairman & CEO, KIK Corporation
- **Lloyd S.D. Fogler, Q.C.**, Partner, Fogler, Rubinoff LLP (Law Firm)
- **Dianne Lister, LL.B., CFRE**, Past President & CEO, The Hospital for Sick Children Foundation
- **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 Linda McKie at 416-923-2999.

# 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.

**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 Cheryl Kanter, Neetu Malik, Stephanie Phan and Maureen Daniels at The Pencer Centre. Patients meet as one group while caregivers meet separately in another room. The groups provide an opportunity for patients and families to connect with others in similar circumstances. It is a chance to share stories, feelings and coping strategies. This is a drop-in program and no prior registration is required. Simply come to The Centre on the evening the group meets.

**Relaxation Therapy.** The ability to relax, especially when facing stressful situations, can have many benefits. Led by our Occupational Therapist Stephanie Phan, our relaxation therapy program offers patients and family members an opportunity to learn a number of useful techniques for relaxation. The program takes place each Wednesday afternoon from 1:00-1:45 pm. This is a drop-in program and no prior registration is required, simply come to The Centre at the above noted time.

**Art Therapy.** Led by well-known art therapist Gilda Grossman, the Art Therapy program uses art as a means to explore and share feelings in a therapeutic and enjoyable way. A highly popular and well attended program, Art Therapy is suitable for all of our patients – whether they are newly diagnosed, or have been living with a brain tumor for some time. No prior art experience is necessary. This program is free but space is limited. For a complete list of upcoming dates or to register, please call Maureen at 416-946-2240.

**Patient Information Binder.** Our Patient Information Binder is as popular as ever. Included in each edition 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, or require additional sheets for your existing copy, 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.

**Radiation Therapy and You Video.** If you are about to undergo radiation therapy, or have already done so and would like additional information about the treatment, our educational video "Radiation Therapy and You" is a must see. This 20 minute video contains information about how the treatment is planned, what types of side-effects are typical, and who to contact should you have questions or concerns. The video may be borrowed from the library in The Pencer Centre and is also available on the radiation therapy treatment units on level 2B. You can also obtain a copy by contacting Maureen at 416-946-2240.

**CD-ROM.** Our highly acclaimed CD-ROM, which contains over 20 hours of information on brain tumors, available treatments, supportive care services and even real life patient experiences, 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.

**Care for Caregivers.** Be sure to watch upcoming issues of *BrainScan* for information about our next Caregiver workshop, slated to take place in Spring 2005. Upcoming issues will announce the date of the workshop, as well as highlight aspects of the program to be presented. Our previous Caregiver Workshop, which ran in the Spring of 2002, was a big success. Since then we have had many requests to repeat the program and we are looking forward to doing so this spring. Stay tuned!

**DID YOU KNOW?**  
**THE BRAIN TRUST HAS A TOLL-FREE NUMBER!**  
**1-877-282-HOPE 4673**

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**BRAINSCAN**

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