

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 THE UNITED STATES



A MESSAGE FROM THE DIRECTOR

Holly Pencer Bellman, Executive Director

SADDLE UP AND SUPPORT The Brain Trust's annual Spring Gala! Toronto's Wildest Western Extravaganza, 'Wild Wild West' will take place on Thursday, June 1st, 2006 at The Liberty Grand Entertainment Complex, Exhibition Place in Toronto with proceeds going

to support The Pencer Brain Tumor Centre at Princess Margaret Hospital. Brace yourself for a 'heel kickin', knee slappin good time at Toronto's hottest event, this year featuring a 'Coyote Ugly' style saloon complete with dancers on the bar, gourmet BBQ fare and kegs of ice-cold beer, live fiddler and line dancing, mechanical bull contest and other surprises. Guests will get down to the sounds of Beverley Mahood & Lace, The Anita Rossi Band and The Shania Show. Be prepared to 'shop till you drop'

at our all new 'General Store' (sponsored in-part by Western Corral) which boasts an eclectic array of merchandise like Western clothing and boots for adults and kids, gorgeous jewellery and accessories, a luxury Fisher Island getaway and other great trips, a candy apple red mercedes pedal car for your little driver (plus many other kid selections), extravagant shopping sprees at TNT, Rainbow and more; and an overflowing restaurant section to name a few. Guests can also load up on Lucky Keys for the chance to win a stunning 5 K diamond necklace and purchase Sheriff Badges in our 'Quick Draw' for the chance to win an all-inclusive Calgary Stampede Getaway. So, dust off your old cowboy boots and don your best denim as you enjoy a down-home party filled with over 1,000 patrons and net proceeds exceeding the half million mark!!

continued on page 6

WILD WILD WEST



PROCEEDS WILL SUPPORT RESEARCH AND PATIENT CARE AT THE PENCER BRAIN TUMOR CENTRE AT PRINCESS MARGARET HOSPITAL

EVENING SPONSOR



THURSDAY, JUNE 1, 2006 AT 7:30 PM

THE LIBERTY GRAND ENTERTAINMENT
COMPLEX, EXHIBITION PLACE, TORONTO

'Coyote Ugly' Style Saloon
Gourmet BBQ and Kegs of Cold Beer
Live Music and Line Dancing
Western-inspired 'General Store'
Bucking Bronco & More

FOR TICKETS CALL {416} 923-2999



CLINICAL TRIALS UPDATE - SPRING 06

by Dolores Dohlah - Clinical Trials Coordinator

The clinical trials department at The Pencer Centre is buzzing with activity right now as we prepare a number of studies for submission to our Research Ethics Board (REB) for review and approval. We are very excited to be able to offer more of our patients the choice of entering into a clinical trial as one more option in their arsenal of treatments to continue with the fight against this disease.

This column will focus on one study in particular that that will be submitted to REB over the next few weeks for review. This is a Randomized phase 3 study looking at Enzastaurin versus Lomustine (CCNU) in the treatment of recurrent, intracranial Glioblastoma Multiforme (GBM).

In this study, participants will be placed into one of two study arms. Arm A Experimental arm will be the one looking at using Enzastaurin administered orally for one day only, every 6 weeks. Arm B will be the Standard arm using Lomustine (CCNU) also administered orally for one day every 6 weeks.

Temozolomide (TMZ) is now part of the standard of care in the first-line treatment for patients with GBMs, and is being given concurrently during radiotherapy and adjuvantly for a period of 12 months.

At recurrence, options are limited, and usually consist of a nitrosourea type of chemotherapy such as Lomustine (CCNU) or entry into a clinical trial. Glioblastomas are known to be very vascular tumours, and this is usually associated with an overexpression of certain growth factors and receptors. In theory, Enzastaurin may have some anti-angiogenic activity, thereby suppressing these pathways. It may also inhibit the activity of other proteins that contribute to tumor growth.

This study will compare these two agents and will evaluate Enzastaurin against Lomustine in recurrent glioblastoma. We anticipate this study will be open sometime in late spring 2006.

Please watch future issues of BrainScan for more information about additional trials as they become available for enrollment. We will always offer those patients that are eligible for a study the option of volunteering to be a study participant.

For further information please contact :

Dolores Dholah at 416-946-4603 or

Leslie Williams at 416-946-4624

CAREGIVER

Don't miss this opportunity to nurture your body, mind and spirit....

The Gerry & Nancy Pencer Brain Tumor Centre invites caregivers of patients living with brain tumors to join us for a one-day workshop devoted to information, education and sharing. Topics to be covered include:

- tips on caring for yourself
- practical tips for coping with a new diagnosis
- parenting during a serious illness
- advice about financial and legal issues
- palliative care
- participants will also have an opportunity to try a selection of complementary therapy modalities such as art therapy, journaling and Tai Chi

Breakfast, lunch and coffee breaks will be provided. This program is made possible through a generous donation from the J. David & Jan Crichton Fund

WORKSHOP

Saturday, June 3, 2006

8:00 a.m. - 4:30 p.m.

The Gerry & Nancy Pencer Brain Tumor Centre,
18th Floor, Princess Margaret Hospital

*Admission is free, but space is limited

*To register, call Sandy Ayers at 416-946-2277

*Registration Deadline: May 26, 2006



still...

defying the odds!



By John Reay

In the Fall 2000 issue of BrainScan, we were pleased to print the story below, written by John Reay. At the time, John had been living with his brain tumor for four years. Once again, BrainScan is pleased to print this update from John, who is, as you will read, still living well and enjoying life nine years after his initial diagnosis.

When I was hospitalized in February 1997 with a suspected brain tumor I was pretty naïve about the subject, as I expect most of us are when we are first hit with this life threatening disease. I knew next to nothing about brain tumors, but as an experienced Internet user I knew where to look for some answers. I quickly discovered, before my diagnosis was even official, that the statistical prognosis is not encouraging for malignant glioma patients. I shed some tears, as all of us do when given the devastating news, but I decided that accepting the diagnosis didn't mean I wasn't going to outlive the prognosis. In fact there was nothing to be gained by dwelling on the statistics. Life is short and none of us, even those with brain tumors, know when our time is going to be up.

I resolved to file away any thoughts of my own mortality and continue living in the best way I knew how. In retrospect, my attitude and my own quiet confidence have been extremely important in coping

with and surviving the challenges that I faced. I have been lucky, there's no question about that. I have a terrific medical team, a loving wife and family, and a will to live and make a difference.

I recently entered my tenth year of living with this thing in my head and I still have no intention of raising the white flag as I've too many other things to do with my life. After all the time that has passed, I'm no longer sure of the diagnosis I was given. Did I really have a glioblastoma as my original pathology report said, or do I have a different, less malignant, tumor as hinted at by a second reading of the same biopsy material? Nobody can say for sure. Either way, I would appear to be lucky, although not so lucky as to have never had this thing at all! I want to share my experience with others so I created a website (<http://reay.dyndns.org>) to tell my story and hopefully show others that statistics aren't everything. You can also find my story on the survivors' pages at <http://virtualtrials.com>.



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

**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.



MAXIMIZE YOUR INDEPENDENCE

Diane Tse is an occupational therapist at The Pencer Centre. In her role as a Rehabilitation Specialist, she works with patients and families to improve and maintain independence and enhance quality of life

by Diane Tse

Q:

I have been living with a brain tumor for about 2 years now, and have received various medical treatments. However, I continue to have some weakness, fatigue, and memory loss, and can't do my household activities as I used to. What can I do about this?

{A}:

People with brain tumors often experience various physical and cognitive changes. However, engaging in meaningful activity is an important part of a good quality of life, and therefore should be encouraged. The aim of rehabilitation

is to help maximize abilities and independence as much as possible.

In your case, I would suggest looking closely at a few of your home activities and exploring what the barriers are. If you are limited by physical weakness or fatigue, you can use energy conservation techniques, or alternate strategies to accomplish the task. For example, taking an extra rest break or sitting down to do the activity goes a long way to conserving energy! You may also benefit from an assistive device, or equipment that could make the task easier or safer, such as a grab bar in the bathtub, or a rail beside the bed. An occupational therapist can help with specific recommendations on home safety and how to manage daily living activities at home or in the community.

If you are limited by memory problems, you may benefit

from strategies such as using a calendar or writing down notes. There are also many gadgets on the market that can help with memory, organization, or provide alarm reminders for activities such as appointments or medications. Sometimes just keeping a regular, predictable routine is enough to help people remember what needs to be done. Again, an occupational therapist can help with specific strategies for your daily activities, and a speech language pathologist may also be of assistance if the memory difficulties are associated with speech and language problems.

If your lifestyle has become more sedentary since your diagnosis and treatments (which is quite common), then you may benefit from some regular exercise or activity program to help increase your overall conditioning. A physiotherapist can help recommend specific exercises that can be adapted to your level of physical ability. He or she can also suggest devices and strategies to improve your mobility.

Lastly, there are many community programs (some are more rehabilitative in focus, while others more social and recreational) that adapt to various levels of ability, and can help you work on specific skills. For example, some community based yoga or tai chi classes will adapt their program to suite different levels of ability. So, as you can see, there are many opportunities to try new activities and new ways of doing things to help you manage the difficulties that you may be experiencing.

If you are interested to learn more about rehabilitation services, please contact **Diane Tse at The Pencer Brain Tumor Centre, 416-946-4501, ext. 3995.**



**“Courage is being scared to death...
and saddling up anyway.”**

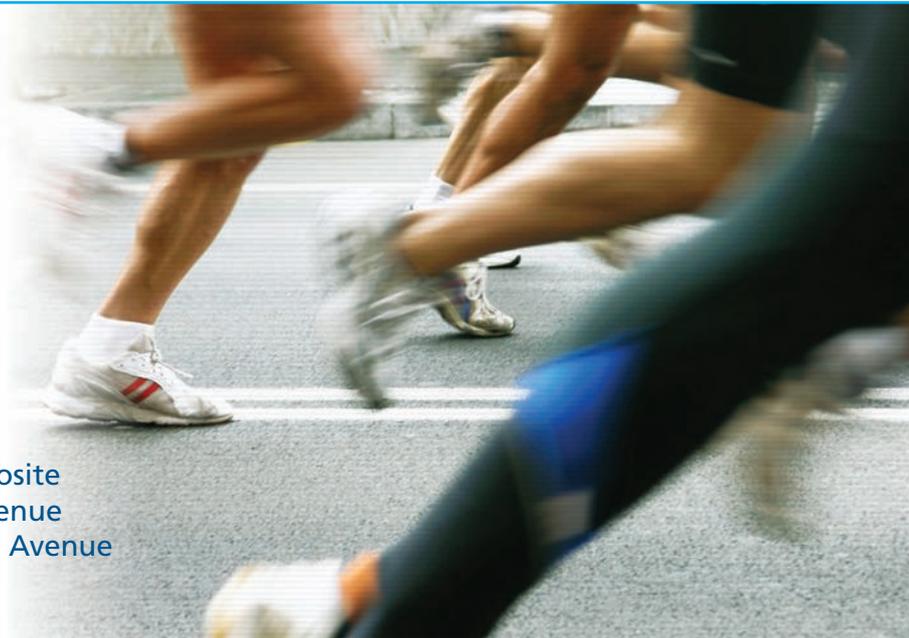
John Wayne

Head for a Cure 2006

Be an early bird! Sign up now to walk or run in the Head for a Cure 2006 5K Run in support of The Gerry & Nancy Pencer Brain Tumor Centre at Princess Margaret Hospital

**Sunday,
October 15, 2006
@ 8:30 AM**

The 5K Run will begin at Queen's Park opposite Hart House and run south on University Avenue to Front Street, turning north up University Avenue and finishing at Queen's Park



Fees: by June 20th - \$25.00 • by September 10th - \$30.00 • After September 10th - \$35.00
Register by October 1, 2006 in order to ensure you receive your Head for a Cure t-shirt

Pledge sheets available at The Gerry & Nancy Pencer Brain Tumor Centre by contacting **Maureen Daniels at 416-946-2240 or online at www.pmhf-uhn.ca**



Dr. Warren Mason, Medical Director, The Gerry & Nancy Pencer Brain Tumor Centre

This Spring Brainscan column provides me with an opportunity to highlight some current and planned activities at The Centre. For starters, we are very excited about a number of clinical trials that are recently activated or are in the process of activation.

There has been an explosion of clinical trials activity following the publication of our trial involving radiotherapy with temozolomide for patients with newly diagnosed glioblastoma. Firstly, we will be participating in a follow-up to this trial, a very large study that will determine whether we can improve survival for patients with glioblastoma if we increase the dose and exposure to temozolomide. This is an important trial that will refine the way we use temozolomide for brain tumors.

Additionally we will be conducting a number of trials with new experimental drugs for a brain cancer, in what is

an international ongoing effort to identify new agents that can be used to treat brain tumors. Finally we have two new studies that will explore the role of radiotherapy and chemotherapy in slowly growing tumors such as low-grade gliomas and meningiomas.

Once again, The Pencer Centre will be organizing a caregiver workshop to provide information, education and support for those who are caring for patients with brain tumors. This weekend programme will take place on June 3, 2006, and since it has been very popular in the past, and always is fully booked, please contact Sandy Ayers at The Centre if you are interested in attending.

Finally, The Pencer Brain Trust is holding its annual gala on June 1, 2006. This year's theme is "Wild Wild West," and it is bound to be the most entertaining fundraising event of the year. So do plan on being there, having a great time, and supporting the activities of The Centre.

**Tharshini Chandra - Psychology Assistant**

For many patients, once their radiation and or chemotherapy treatment is completed, and they begin to rejuvenate, questions may arise about their ability to return to school or work. In other cases, family members may wonder about how much independence a patient can safely manage. At The Pencer Centre, we are pleased to offer, among our team of experts, the services of our neuropsychology department led by Dr. Kim Edelstein. The neuro-psychological staff at The Pencer Centre can provide assessments of the cognitive abilities of patients in order to help identify areas of weaknesses and develop strategies for coping with these issues in the context of day-to-day living or returning to work or school.

Tharshini Chandra is a Psychology Assistant who works with Dr. Edelstein and administers standardized cognitive tests required to provide a thorough assessment for each individual patient.

Tharshini earned her Bachelor of Science degree in Neuroscience from the University of Toronto and has done additional training in cognitive testing and measurement in the Neuroscience Program at London Health Sciences Centre. Prior to joining The Pencer Centre team in December 2004, she worked in a variety of healthcare settings including Trillium Health Centre, The Centre for Addiction and Mental Health, and the Rotman Research Institute, where her responsibilities included conducting neuropsychological assessments of a wide range of patients affected by a variety of neurological diagnoses.

Tharshini explains that in her role at The Pencer Centre, she is responsible for administering and scoring a number of different neuropsychological tests for patients. These tests measure learning and memory, attention and concentration, visual spatial abilities and executive functioning in addition to other cognitive abilities. She goes on to explain that the testing process can be a lengthy and fatiguing one for patients, particularly for those individuals who are undergoing their neuropsychological testing at the same time as their radiation and or chemotherapy. For this reason, Tharshini explains that every effort is made to accommodate the needs of the patient. For example, the testing may be carried out over several shorter testing sessions as opposed to one long session.

Tharshini finds her work at The Pencer Centre both challenging and rewarding. In particular she says this position provides her with the ability to be part of the ongoing care of patients.

In addition to her clinical work, Tharshini is also working with Dr. Edelstein on a number of research projects that will add to our body of knowledge about how cognition is affected by radiation treatment over the long term.

Tharshini says she enjoys working at The Pencer Centre and that “the strength and courage displayed by patients surrounding their diagnosis and treatment is inspiring. Patients continue to be positive and upbeat and I often tell myself that this is something I could learn from them.”

Tharshini's calm and quiet approach to her work, combined with her professional expertise, have made her a valued member of The Pencer Centre team.

Please speak to your oncologist if you think a neuropsychological assessment might be of benefit to you or a loved one.

DID YOU KNOW?

The Pencer Centre has a toll-free number!
1-877-282-HOPE 4673

Directors message continued from page 1

As always, proceeds from 'Wild Wild West' will go to The Gerry & Nancy Pencer Brain Tumor Centre at Princess Margaret Hospital. The corporate and private support for 'Wild Wild West' to date has been overwhelming! For the fifth consecutive year, Cott Corporation has come on board as our Evening Sponsor, TD Securities are back as Décor and Magazine Sponsor, Proprint Services as our Printing Sponsor and David

and Stacey Cynamon as Entertainment Sponsor! New this year, we have Sleemans on board as our Beer Sponsor, Halperin Enterprises as our Wine Sponsor, Harvey Kalles Real Estate sponsoring our General Store Booklet, Roy Foss Motors as our Automotive Sponsor and Western Corral sponsoring our General Store in-part. As usual, 'Wild Wild West' is sure to be a sell-out so buy your tickets now at \$250 each or become one

of our distinguished corporate sponsors. To get on our invitation mailing list, to order your corporate package or purchase tickets, call our **'WILD WILD WEST' hotline at (416) 923-2999** or go on-line at **www.pencerbraintrust.com**

Enjoy a great day of golf for a great cause! Mark Monday, August 28th, 2006 on your calendar for Cott Corporation's 6th Annual Gerry Pencer Golf Tournament. Held at the historic Scarboro Golf & Country Club, proceeds from this great day go to The Gerry & Nancy Pencer Brain Tumor Centre at Princess Margaret Hospital. This exciting tournament is always a hot ticket so arrange your foursome early. For more information, please call Ines Marra at (905) 672-1900 x 19211 or email at imarra@cott.com

Finally, in conjunction with the Toronto Marathon, we hope you'll join us for our Annual 'Head for a Cure' 5K walk on

Sunday, October 15th, 2006. Last year, over 150 eager participants raised in excess of \$45,000 for The Gerry & Nancy Pencer Brain Tumor Centre!! From the bottom of my heart, I say thank you to our Patient and Family Advisory Committee for organizing the day and to all participants for coming out and 'Heading for a Cure'. For more details, check out future issues of BrainScan, log onto The Pencer Centre website (www.uhn.ca/programs/pencer) or The Brain Trust website (www.pencerbraintrust.com) or call Maureen Daniels at (416) 946-2240

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) 923-2999 or hollybellman@aol.com

BRAINSCAN'S IN THE KITCHEN



Spicy Baked Beans

- 1 lb. dried pinto beans
- 1 large onion
- 2 cloves garlic, minced
- 1/2lb. side bacon, chopped
- 1 cup ketchup or barbeque sauce
- 2/3 cup packed brown sugar
- 1 tsp. dry mustard
- 1/2 tsp. crushed hot pepper flakes
- Dash of Worcestershire sauce

Wash and sort beans, discard blemished ones. In a large sauce pan cover beans with 6 cups of water and let stand over night. The next morning, drain well. Add 5 cups fresh water and bring to a boil. Reduce heat, cover and simmer for 1 - 1 1/2 hours until tender. Drain off liquid, reserving 1 1/2 cups.

In a skillet, cook onion, garlic and bacon over medium heat for 15 minutes or until bacon is crisp; add along with fat to the beans. Add reserved liquid, ketchup, sugar, mustard, pepper flakes and Worcestershire sauce, mixing well.

Transfer to a 12 cup bean pot or crock; cover and bake in a 250 degree (Fahrenheit) oven, stirring occasionally, for 2 hours. Uncover and bake for 30 minutes longer or until slightly thickened. (Makes 12 servings)

Bon Appetit!



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:

- **Lawrence S. Bloomberg**, Director & Advisor, National Bank of Canada
- **Richard Cole**, President, R.J. Cole Financial Consulting Limited
- **David Cynamon**, Chairman & CEO, KIK Corporation
- **Dianne Lister**, LL.B., CFRE, Principal, The Dianne Lister Group
- **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.

Patient Information Binder. Our Patient Information Binder just got better! We are thrilled to be able to include the new edition of the "Patient Handbook" from the Brain Tumour Foundation of Canada (BTFC). This recently updated resource is a valuable companion to the Patient Information Binder as it includes a wealth of information about tumors, treatments, medications, and many other subjects of interest to those people living with a brain tumor. Congratulations to BTFC for producing such a wonderful educational resource. Also 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, or if you 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.

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. A DVD copy of this video is now provided to every new patient when they receive their Patient Information Binder. If you do not have a copy and would like one, please contact 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, has recently been updated to reflect

substantial changes in standard treatments. This video 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.

Pencer Centre Website: Be sure to check out our website for updated information about programs at The Pencer Centre, upcoming events and projects, biographies of staff, back issues of BrainScan, and much much more! To go directly to the site simply visit www.uhn.on.ca/programs/pencer.

Open House 2006. Be an early bird...mark Friday, October 27, 2006 in your calendar today, and plan to join us for our Annual Open House event! This is a great opportunity to learn more about the treatments available for brain tumors, as well as the wide variety of supportive care services available to both patients and families. Stay tuned to upcoming issues of BrainScan for further details - such as this year's featured speaker -- as they become finalized.

Head for a Cure 2006: The 4th annual Head for a Cure 5K Run will take place on Sunday, October 15, 2006, in conjunction with the Toronto Marathon. For more information about the event, how to register or sponsor a participant, please contact Maureen at 416-946-2240 or stay tuned to upcoming issues of BrainScan as the details become finalized.

<p>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</p>		<p>Pencer Brain Tumor Centre, Princess Margaret Hospital, 610 University Avenue, 18th Floor, Toronto, Ontario M5G 2M9 Tel: 416-946-2240 or email: maureen.daniels@uhn.on.ca</p>	<p>PRINTING COURTESY OF: </p>
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