

Headlines

Spring 09

A newsletter for brain tumour patients and their families

MEDICAL UPDATE

BrainCare BC

By Dr. Brian Toyota, Neurosurgeon and Head of the Neuro-Oncology Tumour Group

BRAIN CARE BC is an initiative of the Neuro-Oncology Tumor Group (CNS team) at the BC Cancer Agency that seeks to improve the lives of people with brain tumours. To achieve this goal, the CNS team endeavoured to look at the experience of brain tumour patients and their family members from the time of their diagnosis and throughout treatment in order to better understand the issues that are most challenging to them. Perspectives from a number of established brain tumour centres in Toronto and the United States, as well as personal experiences from the participants of the BC Cancer Agency brain tumour support group informed the development of an innovative and enhanced standard of care. BrainCare BC's approach will include seamless patient care, a Clinical Trials Unit, translational research and minimally invasive treatments.

Seamless Patient Care

A fundamental conclusion of our analysis was that the flow of patient care was heavily weighted towards the convenience of the physicians but not of the patient with the tumour. For example, a patient with signs suggesting a brain tumour may be seen by a family doctor, who in turn makes a referral to a neurologist, who then orders a CT scan. If the scan

shows a tumour, the patient is referred to a neurosurgeon, and then must await the surgery date and then wait again for the results of the tumour pathology report. After the report arrives, a referral is made to a radiation oncologist and a medical oncologist, and finally the radiation and chemotherapy treatments are scheduled. Each and every step includes a waiting period, a delay in treatment, a repetition of information and inefficiency.

BrainCare BC proposes a model of seamless patient care. In this arrangement, after the diagnosis of brain tumour has been made, a referral is made to the BrainCare BC Unit. The patient will immediately be contacted by a health



care professional from this unit and information and support will be provided. An appointment is made within a week

to see a neurosurgeon, as well as radiation and medical oncologists. All the necessary information and imaging will be gathered by the BrainCare BC Unit and made available to the involved physicians. The seamless care model will also provide rehabilitative services including physiotherapy,

occupational therapy, speech pathology services, neuro-psychological assessments and nutritional support. By centralizing services, we expect to provide more holistic, timely, patient-focused care; decrease the stress that patients and

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Brain Tumour Tissue Bank

By Dr. Brian Toyota

CUTTING EDGE RESEARCH that will lead to the cure of brain cancer is unfolding on many fronts in laboratories across the world. These strategies include immunotherapies, stem cell research, genetic diagnoses, and molecular manipulations. Despite the broad approach taken by different laboratories, they all have one fundamental requirement: brain tumour tissue.

Brain tumours are simply normal brain cells that have mutated. The genetic

mutations that occur in a cell then lead to a sequence of events that create a malignant mass - a body of cells that grow without restraint and invade the neighbouring normal cells. Researchers want to know why these mutations occur, what the precise mutations are, what events they cause and how the events lead to malignant cell behaviour. Once these facts are understood, treatments to reverse or abort the malignant processes can be undertaken.

In order to conduct this research and *continued on page 3*

Caregiving – A new study recruiting caregivers at the BC Cancer Agency

Vancouver and Fraser Valley Centres
By Shelly Fitzgerald, Study Coordinator

CARING FOR A LOVED ONE with cancer can be a challenging experience. At the University of British Columbia (UBC) and the BC Cancer Agency (BCCA), we are trying to understand the kinds of challenges that caregivers face, and the strategies they use to cope with them. We hope to use this information to make the caregiving experience a bit easier for family members of brain tumour patients.

The director of the project is Dr. Greg Miller from the Department of Psychology at UBC. Dr. Miller first became interested in caregiving more than a decade ago when studying parents whose children were being treated for cancer. He noticed that families differed in their response to caring for a sick child. Some did very well, and others did not. This led him to carry out a series of projects asking questions like: Why is it that some caregivers are able to handle the caregiving experience better than others? What can this teach us about the effect of different attitudes and



From left to right, Rosemary Cashman, Shelly Fitzgerald, Greg Miller and Roy Ma

approaches to caregiving on caregivers themselves? Can different approaches have an impact on caregivers' long-term health? Much of this work has been done in collaboration with Dr. Roy Ma, a radiation oncologist at the BCCA, and has focused on caregivers of patients with brain cancer.

Building on the findings of their previous research, Drs. Miller and Ma have recently been awarded a grant by the Canadian Institutes of Health Research (CIHR). The grant will be used to carry out a new study of caregivers of brain cancer patients. This study seeks to document

the physical effects of caregiving on the body (for example on general health and immune function) and to identify the personal resources (like social support from friends) and coping strategies (like relaxation) that help caregivers to manage this challenging experience. This information will, in turn, help us to develop programs to support future caregivers who may face similar challenges.

Dr. Miller and his team are currently seeking caregivers to participate in this study. To participate, you must be caring for a loved one or friend who is currently receiving treatment for brain cancer. Participation involves four one-hour meetings that will be coordinated with the participant's visits to the BCCA over the course of a year. During each meeting, caregivers will be asked to answer questions about their experience, and will have a blood sample taken to assess their health and immune system function. For three days following each visit, they will keep a diary of their mood and health practices, and collect saliva samples that will be used to measure their stress hormone levels. As a token of our appreciation, participants will receive \$50 for each visit.

Research studies at the BCCA

The BC Cancer Agency is an academic centre affiliated with the University of British Columbia. As such, in addition to providing standard treatments for cancer patients, the BCCA is a Canadian leader in innovative and experimental therapies which occur in partnership with other research and academic institutions. As a result, your experience as a patient may include the opportunity to participate in research studies.

Your oncologist will tell you if there are clinical trials available to test new treatments for your type of brain tumour. In addition to treatment trials, there are studies which attempt to understand your experience as a patient or caregiver, so that we can help you more effectively. At present there are 3 such studies for brain tumour patients and their families and you may participate in one or more of these, including the one featured on this page.

For more information about these types of studies, ask your health care team or contact: rcashman@bccancer.bc.ca

For information about research at the BCCA: www.bccancer.bc.ca/RES/default.htm

For info about clinical trials: www.bccancer.bc.ca/PPI/CancerTreatment/clintrials.htm

Participation in clinical trials and research studies is always voluntary, never obligatory.

For more information about this study, please contact Shelly Fitzgerald at 604 822 5463. You can also reach us by e-mail: caregivers@psych.ubc.ca.

families undergo; and generally improve their quality of life.

Clinical Trials Unit

In an effort to bring promising new therapies to brain tumour patients more quickly, BrainCare BC will include a Clinical Trials Unit (CTU). Clinical trials are designed to establish the safety and usefulness of new surgical, radiation or drug treatments. Indeed, the 'standard' or conventional therapies of today were at one time investigational drugs being studied through the clinical trial process. The CTU will allow access to a greater number of experimental treatments than currently offered for brain tumour patients in British Columbia. In October of 2008, through the support of the BC Cancer Foundation, \$1.5 million was raised to create a brain-tumour dedicated CTU, to open within the year.

Translational Research

Innovative therapies begin in the laboratory, where scientific knowledge and research techniques are applied to the problems of human disease and then translated into new treatments. BrainCare BC is delighted to announce that we have successfully recruited Dr. Stephen Yip, a neuro-pathologist who recently completed a fellowship in brain tumour research and molecular pathology at Harvard University. A meeting was convened in February, 2009 that brought Dr. Yip and a number of other prominent researchers in cancer and brain disease to the table for groundbreaking discussions about the cure of brain tumours. The CNS team and BrainCare BC have developed a business plan to establish up to \$5 million in funding for new brain tumor research in British Columbia.

Minimally Invasive Treatment

One of the goals of brain tumour care is to decrease the need for surgical intervention in treating brain tumours. While this goal may be years away on the horizon, in the short term we have strategized to

make surgery as minimally invasive as possible. This plan includes the creation of an operating suite where surgery on the brain can be done on a day-care basis with the help of state of the art technologies, including intra-operative MRI, laser-assisted thermal tumour ablation and neuro-navigation. Creation of this minimally invasive treatment suite is a BrainCare BC priority.

Brain Tumour Tissue Bank *continued from page 1*

to discover "what make a tumour tick," scientists need access to brain tumour tissue so that they can study the tumour cells of a person with this disease. It is not sufficient to study cells in a Petri dish or in animal models of brain tumours, as these don't reliably represent the behaviour of human brain tumours.

Even more importantly, today the goal is to "personalize" tumour treatment. What this means is that rather than giving the same treatment to many different patients simply because their tumours have a similar microscopic appearance, our goal is to obtain the individual "fingerprint" of a person's tumour. A tumour is as individual as the person who harbours it, and treatments must be individualized to be successful.

In some cases, specific tumour markers indicate the treatment that is most likely to be effective. Often these markers can only be detected in tissue that has been frozen immediately after surgery. The more typical method of preserving tumour tissue leads to degradation of the tumour cells. Hence, tissue preserved by older methods is virtually useless to detect newly discovered tumour markers. As a result of this loss of the unique features of the tumour cells in stored tissue, individual patients may not be identified, now or in future, for promising new treatments that are likely to be effective for their particular tumour. For these reasons, state of the art brain tumour research and diagnosis requires the modern techniques of fresh tissue processing. This process is best served through a tissue bank which has

BrainCare BC envisions a more effective and responsive model of care for people with brain tumours. We have developed a number of aspects of this multidimensional program, and have already established funding for many of them. The coming year will be an exciting time, and we can look forward to significant improvements in the care and treatment of those living with brain tumours.

the expertise required to obtain and store fresh tissue from all patients using the most sensitive methods.

The formation of a tissue bank is a complex process that includes the involvement of an ethics review committee to ensure that all patients who submit their tumour tissue remain anonymous and that their rights are respected. Once approved to proceed, the bank must coordinate with the operating room and pathology department so that the tumour tissue is properly handled, analyzed and processed. Care is taken to ensure that the pathologist receives adequate tissue to make a definitive diagnosis before the tissue is banked.

Despite the clear need to accrue brain tumour tissue in order to advance research, very few brain tumour tissue banks exist in Canada. The absence of a brain tumour tissue bank impedes both basic scientific research and our ability to precisely determine the fingerprint of a patient's tumour. Currently the CNS team, BrainCare BC and laboratory personnel are working to establish a brain tumour tissue bank in Vancouver. Ethics approval is expected within the next months and we anticipate that the bank will be up and running by the late summer. This will be a significant leap in the local effort to cure brain cancer.

Once the Vancouver brain tumour tissue bank is fully operational, new patients undergoing surgery for a brain tumour will be asked for their consent to include their tumour tissue in the bank. We hope that this process will become a routine part of patient care and that patients will welcome the opportunity to facilitate research for themselves and others.



Walk, Run or Sprint! in support of those affected by a brain tumour

Be one of thousands across Canada who will be walking, running and sprinting to support the Brain Tumour Foundation of Canada. The Brain Tumour Foundation of Canada creates hope and provides help through:

- **RESEARCH** into the cause, treatment and cure of brain tumours
 - **SUPPORT GROUPS** in 21 locations across Canada
 - **INFORMATION DAY** conferences with leading medical experts held at various locations across the country (including Vancouver)
- **EDUCATION** through handbooks and other resources and initiatives

Find out more and register online at www.springsprint.ca.

In greater Vancouver, the 2009 Spring Sprint will take place:

Saturday, May 2, 2009

Burnaby Lake (East), 2.5 and 5 km routes

Check-in: 10 am

Start time: 11 am



All enquiries and telephone registrations can be directed to Carol Anthony at canthony@braintumour.ca or 1 800 265 5106 ext. 225
If you'd like to help out at the event, contact Yaron Butterfield at ybutterf@bcgsc.ca or 604 707 5900 ext. 5446
The Brain Tumour Foundation of Canada www.braintumour.ca

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Editions of *Headlines* are also available as a pdf download at:

www.bccancer.bc.ca/HPI/CancerManagementGuidelines/NeuroOncology/PatientResources.htm

If you would like to submit an article, ask a question, or serve on our patient and family advisory board, please contact Rosemary Cashman at rcashman@bccancer.bc.ca or 604 877 6072 (phone) 604 877 6215 (fax).

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