

# Headlines

Summer 10

A newsletter for brain tumour patients and their families

## MY STORY

By Janet Dukowski

ORIGINALLY I STARTED WRITING this article to talk about how I accomplished The Ride To Conquer Cancer. I thought it would be a great way to raise money for cancer research and a great way to help me move forward after finishing my treatments for a malignant brain tumour. I set a goal that I knew would be near impossible to accomplish, but I needed a goal that was almost as grueling as undergoing cancer treatments. I wanted to put my body through a physical challenge on my own terms. Cancer took away control of my life, and The Ride to Conquer Cancer was a way to begin taking it back.

However, after accomplishing this amazing event – a 250 km bike ride from Vancouver to Seattle over two days – I realized that this article had to be about more than just me. There were approximately 3,000 riders and countless volunteers who were all united for the same purpose: to find a cure for cancer. And not only were the riders going the same distance as me, but some of them were on heavy mountain bikes, single speed bikes, and there was even a guy riding a unicycle! I rode with my unofficial team, a group of friends I named my Fab Five, who originally signed up to ride on my behalf. Little did any of us know that I would be joining them! It was their support and encouragement both during training and during the ride that helped me cross the finish line. I was officially part of the Brainiacs team – a group of

brain cancer survivors and their caregivers. With their amazing fundraising abilities, and with much thanks to our team captain and GBM survivor Paul Chapman, the Brainiacs raised over \$100,000 for brain cancer research, and overall the ride raised \$9.2 million for the BC Cancer Foundation!

On the days leading up to the ride, my nerves and anticipation were rapidly rising, and before I knew it was 7am in a parking lot in Guildford and it was time to ride. We had perfect riding weather on the first day, mostly cloudy with sunny periods over fairly flat terrain. The true test came on day 2, when we woke up to a cold, misty morning that turned into rain by lunchtime. Despite our cold, wet feet, and the much more hilly terrain, most people trooped on, because they knew people or had themselves experienced much worse while battling cancer.

We knew that the end of the ride was drawing near as more and more people were out on the streets, despite the persistent drizzle, cheering us on. And to cross the finish line with my teammates is an experience I will never forget! We had cycled 250 km with our bodies and bikes intact, we had our names announced over the loudspeaker, and we had hundreds of people cheering for us and thanking us as we crossed the finish line. It was an overwhelming emotional experience that



The "Fab Five" plus Janet Dukowski (third from the left)

is seared in my mind.

What I learned most during this bike ride is that no one is alone in his or her fight against cancer; it's a team effort. The ride embodied this mentality as riders helped each other get through two grueling days of biking while keeping spirits high. The most memorable moments for me did not involve my own personal struggle; they were riding with my team and meeting new people. Every person had their own cancer story to share, and it was the sharing of these stories, some heartbreaking and others inspiring, that made the ride worthwhile. It was an honour to be able to ride with this amazing group of people.

The Ride to Conquer Cancer is a wonderful event, and for me it was a difficult goal that I needed to accomplish to help me get through my cancer treatments, to move forward after treatment, and to take back control of my life. The most important lesson I learned

*continued on page 2*

# Update from the American Society of Clinical Oncology (ASCO) 2010 meeting, Chicago

**T**HE ASCO MEETING occurs annually and is an important source of information about treatments for all types of cancer. Oncologists attend these meetings to identify the most promising new therapies, so that they can recommend these for use in their treatment centres. Unfortunately, this year the brain tumour treatment reports were disappointing. For one thing, the results of some important clinical trials were not presented. These include some vaccine trials, such as the EGFRvIII vaccine and the CDX-110 vaccine. Another study of great interest that was not presented evaluates the modification of the dose of temozolomide chemotherapy received after combined chemotherapy and radiation. In this study, one group of patients receives the current standard dose of adjuvant temozolomide, while the experimental group receives an intensified adjuvant temozolomide dose. We'll look forward to these results.

Most of the trial results presented this year focused on treatment for patients over age 65. These trials compared different dosing schedules for chemotherapy and radiation in the combined chemoradiation treatment that is now the standard for patients with aggressive brain tumours who are under 65 years old. Overall, the differences in outcomes were slim and suggest that ongoing research is critical to determine the best way to treat older patients with malignant brain tumours. At present, the BC Cancer Agency is heading up a crucial clinical trial for patients over 65, the **CE.6 study**. This study is also enrolling patients

at other sites in Canada, Europe and Australia, and compares treatment with radiation alone, given over three weeks, to radiation plus temozolomide, given over three weeks. Patients receiving the combined therapy also receive adjuvant temozolomide after completing the combination chemoradiation step. The results of this study are eagerly anticipated and will help to define optimal therapy for this subgroup of patients.

The only new treatment presented at the conference that actually compared an experimental treatment to a standard treatment (a **phase III clinical trial**) was a trial in recurrent glioblastoma of NovoTTF versus the study physician's best choice of standard chemotherapy. NovoTTF is a treatment using electrodes bandaged to the patient's shaved head and plugged into a battery pack to deliver low intensity

electromagnetic fields that hypothetically disrupt cell division. Although the treatment appeared to be safe, it didn't produce outcomes that were significantly better than the chemotherapies the physicians chose as treatment for their patients in the study. NovoTTF has received a lot of publicity and reports about its effectiveness have been controversial at best. In fact, in this previously treated group of study patients, average survival was extended by a few weeks only for the group receiving NovoTTF. When the inconvenience of living with implanted electrodes is factored in, those few weeks may not be a meaningful step forward.

Better treatments are clearly needed for brain tumours and there is considerable effort underway to find these treatments.

*By Dr. Brian Thiessen, Neuro-oncologist*

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## *The Ride To Conquer Cancer* continued from page 1



The triumphant cyclists at the end of the Ride. Janet is 2nd from the left.

from this experience is that I am not alone in my fight against cancer, and that there are people who are equally as dedicated to finding a cure for this devastating disease. I would like to thank all the volunteers who made this event possible, and to my wonderful healthcare team, the brain tumour support group, and my family and friends who supported me through this difficult year.

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

[www.bccancer.bc.ca/PPI/copingwithcancer/specificresources/Neurooncology.htm](http://www.bccancer.bc.ca/PPI/copingwithcancer/specificresources/Neurooncology.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](mailto:rcashman@bccancer.bc.ca) or 604 877 6072 (phone) 604 877 6215 (fax).

All content by Rosemary Cashman unless otherwise specified.

*hope & support*

# BRAIN TUMOUR INFORMATION DAY CONFERENCE



**BC Cancer Agency**

CARE + RESEARCH

*An agency of the Provincial Health Services Authority*



## Saturday, October 23, 2010

8:30 a.m. to 3:15 p.m.

BC Cancer Research Centre  
675 West 10th Ave., Vancouver, BC  
(across from BCCA, Vancouver Centre)

### PROGRAM

8:30 a.m. – 9:00 a.m.  
Registration and Coffee

9:00 a.m. – 9:15 a.m.  
Welcome and Opening Remarks  
Linda Matwichuk

9:15 a.m. – 10:00 a.m.  
Brain Tumour Basics  
Dr. Brian Thiessen

10:00 a.m. – 10:35 a.m.  
Surgery and Brain Function  
tbd / Dr. Brian Toyota

10:35 a.m. – 10:50 a.m.  
Refreshment Break

10:50 a.m. – 11:20 p.m.  
Advances in Radiotherapy for Brain Tumours  
Dr. Alan Nichol

11:20 p.m. – 12:15 p.m.  
**Concurrent Sessions:**  
Caregiver Support Group  
Maureen Parkinson  
Patient Support Group  
Douglas Ozier  
Gentle Yoga Session  
Jan Blades  
*and informal networking for patients*

12:15 p.m. – 1:15 p.m.  
Lunch

1:15 p.m. – 2:00 p.m.  
**Concurrent Sessions:**  
Living with Cognitive Impairment  
Alison McLean  
Stress Reduction / Relaxation Therapy  
Sarah Sample

2:00 p.m. – 2:30 p.m.  
Feeling Your Best: Living with Seizures, Fatigue  
and Other Symptoms and Side Effects  
Rosemary Cashman

2:30 p.m. – 3:00 p.m.  
Complementary Therapy:  
Making Decisions That Are Right For You  
tbd

3:00 p.m. – 3:15 p.m.  
Final Remarks  
Dr. Brian Toyota

**Register Now, Space is Limited!**  
**Saturday, October 23, 2010 in Vancouver, BC**

Presentations by oncologists and other health care specialists

Networking, support groups and more

Lunch provided

All **FREE** to patients, their caregivers and health care professionals

**Registration Required**  
Contact 1.800.265.5106 ext. 231

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& Merck Canada**



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**Q** My surgeon told me that I have a low grade tumour, but then when I got to the cancer agency, I was told that it was malignant and I have to have treatment. I don't know what to believe now. How can a mistake like this happen?

**A** The diagnosis of a brain tumour is performed by a pathologist who has undergone additional training in diseases of the brain, spinal cord, nerves and muscles. A pathologist is a medical doctor who determines the diagnosis of disease through the examination of cells, tissues and organs. This type of study is the mainstay of cancer diagnostics. Radiologic and molecular information also provide important information to further clarify the diagnosis.

Brain tumours are also classified using a standardized grading scheme that has been developed by the World Health Organization (WHO). This allows cancer specialists to "speak the same language" regarding the features of tumours, from the most benign (grade I) to the most malignant (grade IV). Establishing the tumour grade will help tailor treatment and will also suggest how the tumour will behave.

Even with these efforts to be consistent and clear, a precise brain tumour diagnosis may be challenging to make for a number of reasons:

1) **The diagnosis is dependent on the chunk of tumour being analyzed, and this may not be representative of the entire tumour.** Brain tumours, especially gliomas, are extremely *heterogeneous*, meaning the cells within the tumour vary considerably, with some possessing very malignant traits and others appearing more benign. Surgeons and pathologists are very familiar with this feature of brain tumours and try to safely remove and review a sample (or samples) of the tumour that will give a fair assessment of all the cells contained within it. The tumour is classified according to the most malignant cells found in the tissue. However, every cell in the tumour cannot be examined,

and sometimes only a very small portion can be safely removed. Thus there is the possibility that the sample may not include more malignant areas of the tumour.

2) **The grade of the tumour changes over time.** Brain tumours such as astrocytomas and oligodendrogliomas, generally undergo malignant transformation with time. The longer a person lives with one of these tumours, the more likely it will accumulate genetic changes (mutations) leading to a more malignant tumour with more aggressive behaviour. If the same individual has a second or third surgery, the pathologist who reviews the tumour samples from these operations may identify the histological features of increasingly malignant cells. Otherwise, one can only observe the way the tumour behaves (i.e. how it responds to treatment, how quickly it grows, and so forth).

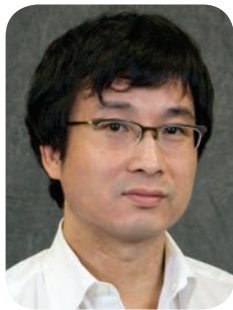
3) **Some tumours are so unique that they**

**do not fit our usual classification systems.** All brain tumours result from accumulated cell mutations, and this process may result in a tumour that seems to be in a class of its own. These challenging cases often display "classic" features of multiple tumours and must be classified in a descriptive way to reflect the complex nature of the tumour.

In these cases, sometimes the most important information that the pathologist can provide is the degree of malignancy of the tumour as reflected by the growth rate, the presence of blood vessels to nourish the growing tumour, and tumour necrosis (or dead tumour cells). The death of tumour cells occurs when the tumour is growing so rapidly that the blood vessels cannot supply adequate nutrition, and the tumour starves. Pathologists often discuss these complicated cases with their colleagues in other cancer centres for additional opinions and to try to achieve a consensus about the diagnosis.

*By Dr. Stephen Yip, MD, PhD  
Neuropathologist, BCCA, Vancouver*

## Question + answer



WHO grade	Example	Histopathological features
I	Pilocytic astrocytoma	<i>Non-infiltrating</i> (cells are arranged in a single clump)
II	<i>Low grade glioma</i>	<i>Infiltrating</i> . Increased numbers of cells; varied and abnormal shapes of cells and nuclei ( <i>pleomorphism</i> )
III	<i>Anaplastic glioma</i>	Features of grade II + increased cell division ( <i>mitotic activity</i> )
IV	Glioblastoma multiforme	Features of grade III + abundant new blood vessel growth ( <i>vascular proliferation</i> ) and dead tumour cells ( <i>necrosis</i> )

Note: Although grade I and II brain tumours may be considered "low grade," grade II tumours are infiltrating, meaning they spread cells within the brain that cannot be entirely removed by surgery. In addition, grade II tumours have a significant tendency to become more malignant over time ("malignant transformation"). In simple terms, no tumour growing inside the brain tissue should ever be considered benign. Only a small fraction can be removed totally by surgery, and even the slowest growing tumor can be lethal if left to grow unchecked within the closed space of the skull.

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For more information on how you can support enhanced patient care, patient information and brain tumour research, please contact Sharon Kennedy at the BC Cancer Foundation, 604 877 6160 or 1 888 906 2873 or skennedy@bccancer.bc.ca