

Headlines

Summer 11

A newsletter for brain tumour patients and their families

MEDICAL UPDATE

ASCO 2011

IN JUNE I ATTENDED the American Society of Clinical Oncology (ASCO) meeting in Chicago. This is the largest international oncology meeting in the world and attracts cancer specialists from near and far. There was some exciting news for certain cancers such as metastatic melanoma, but I was most interested to learn news that would be important for brain tumour patients.



The study results of particular interest to neuro-oncologists were related to the RTOG-0525 clinical trial. In 2004, the treatment for glioblastoma changed dramatically with the results of a clinical trial that showed us that adding the chemotherapy drug temozolomide (TMZ) to radiation therapy resulted in better outcomes for patients. Since that time, investigators have been trying to find ways of improving on this combined chemoradiation treatment, sometimes called the "Stupp regimen" after the lead investigator, Roger Stupp from Switzerland.

RTOG-0525 was a large phase III trial designed to answer the question: Will more aggressive treatment with TMZ improve outcomes compared to the standard Stupp regimen? Investigators hypothesized that using prolonged doses of TMZ chemotherapy could overcome the development of tumour resistance to

TMZ, a major cause of treatment failure for many patients with glioblastoma.

Many glioblastoma tumours harbour an enzyme called methylguanine methyltransferase (MGMT) that limits the effectiveness of the standard 5 days per month dose of TMZ. This enzyme repairs damage done by chemotherapy to the tumour DNA, thus preventing tumour cell death. It was hoped that by giving more prolonged doses of TMZ this enzyme could be depleted and tumour cell sensitivity to TMZ could be restored.

The study design involved randomizing patients into two groups after the initial combined chemoradiotherapy with daily TMZ. After the initial treatment, one group of patients received standard adjuvant TMZ (5 days every 28 days) for 6-12 cycles, but the other group received "dose-dense" TMZ (21 days every 28 days) for 6-12 cycles. Over 1,000 patients were registered and 750 patients were randomized to the two treatment arms.

The data was presented by Dr. Mark Gilbert of M.D. Anderson Cancer Center in Texas. The results showed that the patients in the dose-dense treatment arm did not have better control of their tumours compared to those that received TMZ the standard 5 days per month fashion. Additionally, the dose-dense regimen was

more toxic and caused more blood count problems and fatigue than the standard regimen.

Fortunately it wasn't all bad news. The investigators were able to demonstrate that methylation, or depletion, of the

MGMT enzyme clearly predicts favourable outcome in this disease. While this had been shown previously in a smaller group of patients, this study conclusively proved that MGMT is an important genetic marker in glioblastoma.

No other large clinical trials were presented

at the meeting, but there were several smaller trials of new agents added either to the Stupp regimen or to bevacizumab. Bevacizumab (Avastin®) has rapidly been adopted as a therapy for relapsed malignant gliomas. So far, as of ASCO 2011, no additional agent has been identified to improve upon the current Stupp regimen or bevacizumab therapy.

There continues to be intense effort within the neuro-oncology community in finding improved treatments. On the horizon, we can expect to see improvements building on the success of the Stupp regimen as well as treatments used in combination with bevacizumab.

*By Dr. Brian Thiessen, Neuro-oncologist
BCCA, Vancouver Centre*



The Ride to Conquer Weather?

IT'S 4:45 ON SATURDAY MORNING of June 18th and my husband Rob and I get up and get ready for our second annual Ride To Conquer Cancer – a 2-day, 250 km bike ride from Vancouver to Seattle. It's raining when we get up; it rains even harder as we drive out to Cloverdale to the start line, and it pours when we arrive on site. Although we have quite a lot of rain gear, we decided to opt out of buying shoe covers, because we were hopeful that the weather couldn't possibly be rainier than last year. Oh, how wrong we were. So as we sat in our truck with the heater cranked to high, we layered ourselves for warmth, put on our rain-proof outer layers, and tied plastic bags around our socked feet and stuffed them in our shoes to keep them as warm and dry as possible (which worked quite well, by the way).

After loading our bags onto the big trucks that haul it all to the first day's campsite, we slop our bikes over to the start line where we wait with the 2800 other riders who have come out for this event. And despite the rain and the unseasonably cold weather, there's a feeling of optimism and hope in the air. People are smiling and laughing and cheering. It's 7 am, we're in a parking lot in Cloverdale, most of us are wet and shivering, yet we can't help but feel an overwhelming sense of accomplishment. We have just managed to raise \$11.1 million for cancer research, which has set a record as the single largest fundraising event in BC history. Our feet may have been cold, but our hearts were warm. We were all a part of a much bigger whole – a big step closer to making cancer history.

The weather slowly improved over the course of the day, and we were thankful

that it was dry while we hung out at camp. And even though I saw it all last year, I was once again in awe of the sheer size of camp. There were rows upon rows of tents to accommodate all the riders, a huge main tent where we all sat to eat, and 5 trailers that held multiple shower stalls. Not only that, but there were bike mechanics working late into the night fixing bikes, there was a massage tent, a yoga tent, and a medical tent – all staffed with friendly, helpful volunteers. There were also lots of line-ups around camp. How could there not be with 2800 people to look after? But this was the time to get to know the stranger in front of or behind you, and to hear why they were riding and whom they were riding for. Mother Nature decided to take over soon enough, and after packing up our gear, returning it to the truck, and getting ready to head back out on our bikes on the morning of day 2, the rain returned, and so did the plastic bags around our feet. But just like the previous morning, our spirits couldn't be dampened.

In a way, having to ride in cold, wet weather seemed fitting. This ride wasn't meant to be easy, just like battling cancer isn't easy. It helped us find inner strength and optimism during less than ideal conditions, similar to the emotional struggle that cancer patients have to face. We also had to experience numb feet and hands, physical fatigue, and various other aches and pains, which are the same types of side effects that cancer treatments offer patients. It reminded me of the emotional and physical struggles that I went through



less than two years ago, while I underwent surgery, radiation, and chemotherapy for my brain tumour. It also reminded me how I had overcome those struggles, and solidified why this ride means so much to me. It's my way of giving back and saying thank you to my healthcare team, my family, and my friends for their dedication, their love, and their support. But as Alfred Wainwright, the long distance hiker of the English Lake District once said, "There's no such thing as bad weather, only unsuitable clothing," so next year I'm coming prepared with shoe covers!

I would also like to thank Paul Chapman, a fellow brain tumour survivor, and Ray DeMeyer, who co-captained our "Brainiacs" team this year. Our team of 16 riders raised \$68,800 for brain tumour research. Way to go Brainiacs!!

By Janet Dukowski

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The International Brain Tumour Alliance

THE INTERNATIONAL BRAIN TUMOUR ALLIANCE (IBTA) www.theibta.org was established during the World Federation of Neuro-Oncology meeting held in Edinburgh, United Kingdom, in 2005. Canadians Rosie Cashman (BC Cancer Agency Nurse Practitioner and Editor of Headlines, Vancouver) and Maureen Daniels (Pencer Brain Tumour Centre Coordinator, Toronto) were both present at the inaugural meeting.



The IBTA does not seek to be a competitor for the national brain tumour support and research organizations, such as the Brain Tumour Foundation of Canada, which are well established and appreciated by the populations they serve.

Instead, IBTA's mission is to raise brain tumour awareness on a *global* scale, primarily through its publications and the two annual projects of the **Walk Around the World for Brain Tumours** and the **International Brain Tumour Awareness Week** (30 October – 5 November 2011), which were supported by 197 organizations worldwide in 2010. IBTA members also attend important international and regional conferences in

the neuro-oncology area where they can exhibit publications and meet with key world leaders in this field.

During each of the past four years the IBTA has prepared and distributed a major publication. The first publication was a report in 2008 on the first Walk Around the World for Brain Tumours (which took place in 2007) and the second was a detailed booklet on the first documented operation for a glioma brain tumour, to mark the 125th anniversary of that event in 2009.

In the next two years the IBTA published a magazine entitled "Brain Tumour" containing interviews with patients, researchers and specialists, and news items about developments in the international brain tumour community. In 2010, this free magazine was sent to recipients in 83 countries.

The two IBTA Co-directors, Denis Strangman (Australia) and Kathy Oliver (UK) are able to draw on the contacts they make during their attendance at meetings and conferences and their unique oversight of developments all over the world, not just in one location, but in North America, Europe, Asia, Africa, and elsewhere. Between them they have met personally with the leaders of all the major national brain tumour patient



Denis Strangman and Kathy Oliver with copies of the IBTA magazine at the IBTA display at the 2010 ASCO Conference.

organizations in existence. In May, while visiting Canada en route to the American Society of Clinical Oncology (ASCO) conference in Chicago, Denis Strangman took the opportunity to attend the monthly brain tumour patient support meeting held at the BC Cancer Agency in Vancouver.

The IBTA is a completely voluntary organization with no paid staff. Funds raised each year are invested in the IBTA's work and enable their publications to be distributed for free within the international brain tumour community. Since 2005 the IBTA has developed a unique database of over 6,000 worldwide contacts who receive their publications. The database includes patients, caregivers, drug and device developers, researchers, specialists, journalists, etc. Monthly electronic E-News bulletins are also sent to these people.

After two annual issues of "Brain Tumour" magazine in 2010 and 2011, Denis and Kathy believe they have identified a formula and content mix which meets a need worldwide.

Kathy Oliver is a former freelance journalist and Denis Strangman spent over twenty-five years as a researcher in the Australian Parliament. They both endeavour to translate major conceptual developments in the brain tumour community into easily understood articles in the IBTA publications, including its magazine and E-News.

After receiving the 2011 issue of the IBTA's magazine, "Brain Tumour," a US reader wrote: "Gosh, it is full of information and hope. The content is certainly chock full of many articles of interest to the international brain tumor community. A popular saying here in the US is 'Think globally. Act locally.' Thank you for helping us to think globally."

A ten-year glioblastoma (GBM) survivor wrote: "It looks great ... my husband read the whole thing and kept telling me how great it is. Amazing stories about survivors. Thank you very much for pulling it together! I am sure it is encouraging so many people all over the world."

With these words of encouragement Kathy and Denis hope to continue their work of raising awareness about brain tumours internationally for as long as they are able.

By Denis Strangman

Q I was diagnosed with a brain tumour in 2009 and finished my chemo and radiation a year ago. I feel great and I want to go back to school to finish my degree. How can I plan for a successful return to school?

A The demands of university are intense and you are wise to plan ahead to give yourself the best chance for success. Brain tumours and their treatments may result in changes in your thinking abilities, such as problems with short-term memory, attention and concentration. You may also find changes in your physical capacities, such as a lower energy level, muscle weakness, or changes in vision, hearing or mobility. If your problem is restricted to fatigue, I would suggest that you initially return to school on a part-time basis and allow yourself some time to adjust to the work demands.

However, if the changes you or others notice in your abilities go beyond fatigue, ask your doctor if this is expected, whether it is likely to improve or continue, and whether a rehabilitation program might improve your function.

Physical disabilities: If you have physical challenges that might affect your ability to get to classes, see course materials, hear lectures, or write notes, an assessment by a specialist clinician can help to identify your strengths and challenges and offer recommendations to improve function. For example, a physiotherapist might help you to improve strength and balance. An occupational therapist could recommend aids to help you get to your classes on time, or strategies for working within your energy restrictions. You might also benefit from technical aids (i.e. computer software with

large print or voice programs for the visually impaired). A provincial program called the Employment Program for Persons with Disability (EPPD) www.mhr.gov.bc.ca/pwd/eppd.htm offers vocational counseling, assessments and assistance for those returning to work or school programs.

Cognitive disabilities:

If you notice changes in your ability to concentrate, attend, remember, sort out new problems, stay on task or multitask, an educational or neuropsychological assessment can specifically identify your weaknesses and offer strategies for dealing with them.

Neuropsychological

assessments are performed through private offices of specially trained psychologists and the costs vary. EPPD offers funding for these assessments in some cases. They are also available at some rehabilitation hospitals, although the wait for these can range from a few to several months. Mindworks www.mindworksgroup.ca is a government-funded program that offers vocationally oriented assessment and rehabilitation for individuals living with impairment in brain function (available to those who do not have private long term disability insurance).

Accommodation: Universities offer services through their counseling or special access departments for those recovering from illness or coping with a disability. These services provide support (counseling, advocacy, learning assistance) to optimize your ability to participate fully in your university program. These supports may include improved access to the classroom for those with challenges to mobility, or provision of frequent breaks for those

suffering from fatigue. If you have difficulty concentrating or remembering, accommodations might include providing you with a note taker or recordings of lectures, or having more time to write an exam or complete essays. In most cases, the university/college will require a letter from your doctor outlining your particular challenges, and may also request a full assessment of these disabilities. It is important to be proactive in organizing these services a few months before you start school so that your particular needs will be addressed without delays.

Financial Support: Another good reason to contact the disability supports or counseling departments at your university or college is to identify any sources of financial support that might be available to you. There are scholarships specific to particular schools and even to those with specific disabilities. The Cancer Survivors Fund of Canada has scholarships for those who have had cancer www.cancersurvivorsfund.org. As well, those who have had a childhood cancer can apply to the Childhood Cancer Foundation of Canada <http://childhoodcancer.ca/search/node/scholarship> and there are additional scholarships available to those who are entering Medicine, Health Sciences or Pharmacy programs. If you were treated through B.C. Children's Hospital you can apply for Balding for Dollars www.baldingfordollars.com/bursary.php. Other helpful scholarship websites include: www.studentawards.com and www.scholarshipscanada.com.

If you would like more information about preparing for university/college or require assistance in obtaining assessment, rehabilitation or accommodations, please contact Maureen Parkinson, 604 877 6000 local 2189 or 1 800 663 3333 local 2189.

By Maureen Parkinson, M.Ed., CCRC, Vocational Rehabilitation Counsellor

Question + answer



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

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 or 604 877 6072 (phone) 604 877 6215 (fax).

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