

BC Cancer Agency www.bccancer.bc.ca

Headlines

Winter 16 *A newsletter for brain tumour patients and their families*

Second World Summit of Brain Tumour Advocates



Photo courtesy of Katherin Wermk, www.barcelonaphotographer.com

THE INTERNATIONAL BRAIN TUMOUR ALLIANCE (IBTA) held its second World Summit meeting in Sitges, Spain in October, 2015. The Summit brought together patient advocates from 27 countries, including patients, family members, health care professionals (nurses, psychologists, physicians), directors of patient organizations and representatives of the pharmaceutical industry. Rosemary Cashman, Nurse Practitioner at the BC Cancer Agency and an IBTA advisor, attended as a Canadian delegate.

There were three keynote speakers: Roger Stupp (oncologist) from Switzerland

who presented an overview of current brain tumour treatments and some recent advances; Martin Taphoorn (neurologist) from the Netherlands who discussed quality of life issues; and Garth Cruikshank (neurosurgeon) from the United Kingdom who reviewed neurosurgical

approaches to treatment.

Every participant in the conference was responsible in some way for a session, either by leading a discussion, facilitating a workshop or participating in a panel.

Topics included:

- Patient and caregiver support
- Presentation and moderating skills for patient advocates
- Fundraising for research
- Expediting the clinical trial process to improve access to novel therapies
- Branding, marketing and legal aspects for patient organizations
- Political lobbying
- Communicating with the media
- Managing volunteers
- Quality of life

Plenary sessions focused on reports from various countries and highlighted some of the unique challenges, cultural barriers and tremendous efforts made by advocates in the developing world.

ADVOCACY, AWARENESS-RAISING AND INFORMATION

The International Brain Tumour Alliance (IBTA) is a unique global network for brain tumour patient and carer groups around the world. We work alongside, and represent, members of our community - including researchers, scientists, clinicians, nurses and allied healthcare professionals - to engage in advocacy, to raise awareness and to share information.

For more information about the International Brain Tumour Alliance, or to receive updates about brain tumour news around the world, see www.theibta.org

Current molecular markers in brain tumour diagnosis and treatment decisions

Note, these markers may be more useful in combination rather than as single markers.

MGMT (methylguanine methyltransferase)

Usefulness – prognostic and predictive
MGMT methylated tumours are associated with better outcomes for patients. In patients over 60 years old, MGMT methylation also directs treatment. Patients in that age group with methylated tumours are more likely to respond well to chemotherapy and patients with unmethylated tumours may be treated with radiotherapy alone.

1p/19q (short arm of chromosome 1 and long arm of chromosome 19)

Usefulness – prognostic and predictive
1p/19q chromosomal co-deletion. This is also called loss of heterozygosity (or 1p/19q LOH) and is associated with oligodendrogliomas. Patients with oligodendroglial tumours tend to have better outcomes than those with astrocytomas. This marker predicts a good response to both chemotherapy and radiotherapy.

IDH1/2 (isocitrate dehydrogenase 1 and 2)

Usefulness – prognostic
IDH mutations in tumours are associated with better outcomes for patients. This mutation is rare in glioblastoma (grade IV gliomas) but common in other gliomas.

ATRX (alpha-thalassemia/mental retardation syndrome X-linked)

Usefulness – diagnostic and prognostic
ATRX mutation indicates that the tumour is an astrocytoma. This mutation does not occur in tumours with 1p/19q co-deletion.

EGFR (epidermal growth factor receptor)

Usefulness – diagnostic
EGFR alterations are common in many cancers, including glioblastoma. Gene amplification (extra copies of the EGFR gene) is the most common alteration. EGFRvIII variant is a common mutation in glioblastoma and may be a target for therapy.

Q I am a new patient at the BCCA and will soon be starting treatment for a grade 4 glioblastoma. I have some questions about treatment.

My brother is a pathologist and tells me that I should have some additional tests done on my tumour, like MGMT and EGFR, but these are not done at the BCCA. How can I get these done and why are they not routinely done at the BCCA?

A Molecular tests like MGMT and EGFR can have value in 3 primary ways: 1) Diagnostic – may aid pathologist in confirming diagnosis, 2) Prognostic – may help the physician know how long a patient is likely to survive and 3) Predictive – may tell the physician which treatments will work best.

The highest value is obtained from *predictive* tests where management will be changed based on the test outcome. EGFR testing offers only limited *diagnostic*

information at this time. It is neither prognostic nor predictive in glioblastoma. MGMT methylation status has *prognostic* value for glioblastoma patients but has *predictive* value only in elderly patients with glioblastoma. Therefore this test is routinely done and the cost is covered for patients older than 60 where it likely will change management options. It would be nice to know from a prognosis standpoint, but unfortunately our health care budget does not cover the cost.

So, in cases where the testing is not covered, patients do have the option to go through the arduous process of getting tested

at another lab. This is challenging as it requires the cooperation of the pathology departments to send tissue and also a means to bill patients for the test. Canadian pathology labs, however, do not typically have a mechanism for billing individual patients.

Question + answer



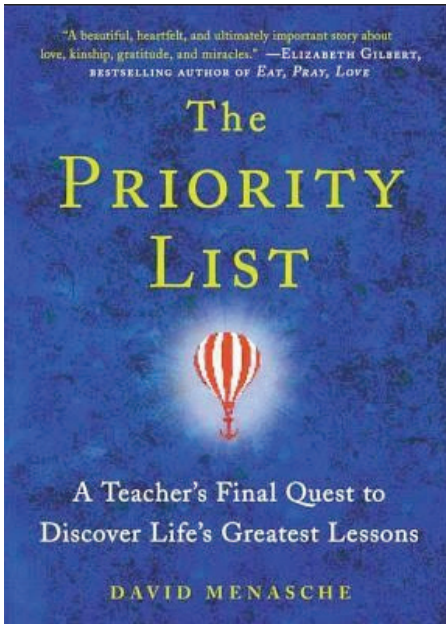
Q My brother is also encouraging me to go to Duke University for the polio vaccine. How can I do that? It sounds like there are other treatments that are very promising but they are all in the U.S. Can the BCCA help me get these?

A *Clinical trials* are studies that are designed to safely test experimental therapies to learn if they can be effective for a particular disease. In order to ensure patient safety, the clinical trial process is heavily regulated and access to the experimental treatments is very limited. Patients can only receive these experimental agents through a properly designed clinical trial at an academic medical centre with trained personnel. The companies providing these experimental therapies will only run clinical trials in a handful of centres initially to keep costs down during the trial phase. As such, not all centres can use all experimental agents. The BCCA has been involved in several major clinical trials for experimental therapies for brain tumours over the years, including the pivotal trial that determined that temozolomide with radiation was superior for glioblastoma

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The Priority List

Review by Yaron Butterfield
 Author: David Menasche
 Touchstone Press, 240 pages
 ISBN 9781476743448; January 2014



I ENJOYED THIS BOOK by a high school English teacher who had a profound influence on his students' attitudes about life. Early on in the book it is clear that he was passionate about his role as a teacher and aimed to have a

positive effect on his students. One of his techniques was to engage his students to develop a "priority list" of guiding ideas and principles that were important to them.

In 2006, he was diagnosed with a glioblastoma and ultimately withdrew from teaching as the diagnosis took its toll on his memory, vision and mobility.

When he could no longer work, he embarked on a tour throughout the United States, meeting his students from previous years. Through his travels and the rekindling of relationships with former students, he learned how their priority lists changed over the years and also how we all struggle to achieve our goals in life.

One thing that I noticed while reading the book is the lack of attention he gave to his wife compared to his students. This seemed to be partly due to what he had been through with the cancer and how this drove him in new directions. This made me think of how the experience with cancer can create new goals and inspirations that affect not only the patient, but also his or her loved ones.

It made me consider how much my cancer experience affected my own personal relationships. I wondered if the

changes in my relationships were due to my new priorities and attitudes, or to side effects of my disease and treatment. What do others believe?

The author passed away in late 2014, but I understand that Warner Brothers is interested in producing a movie about the book with Steve Carell playing the author. I recommend the book as it is well written and thought-provoking.



David Menasche, photo by Chris Granger

Question + answer
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patients than the previous standard therapy. Unfortunately we cannot run every clinical trial and we will never be offered every clinical trial as that process is largely at the discretion of the pharmaceutical industry.

When we have a clinical trial running at the BCCA, we make every effort to offer it to eligible patients. But it is next to impossible to keep track of every clinical trial occurring worldwide. As such, our role in helping patients who are interested in clinical trials elsewhere is limited to reviewing the trial with them to ensure they are eligible, sending information to

the trial coordinator at the study centre, and coordinating with the study centre for appropriate follow-up care. Since all these trials involve experimental agents, it is impossible to advise patients as to which ones, if any, may be more promising. The clinical trial landscape is littered with "promising" treatments that failed, whereas successful new treatments sometimes come from studies that

escaped the media's attention.

For more information about molecular testing for your tumour, speak to your health care team.

For more information about clinical trials see www.clinicaltrials.gov and www.bccancer.bc.ca/our-research

Dr. Brian Thiessen, Neuro-oncologist, Vancouver Centre

This newsletter is published through the generous support of the BCCA Neuro-oncology Fund. For more information about how you can support enhanced patient care, patient information and brain tumour research, please contact Alyson Meehan, Director, Principle Gifts at the BC Cancer Foundation TOLL FREE at 1 888 906 2873 or by email at ameehan@bccancer.bc.ca

Callanish: A healing space for people affected by cancer

CALLANISH IS AN ORGANIZATION that provides counselling, retreats, yoga, music and art therapies and support groups to cancer patients and their loved ones. Callanish's home is in Vancouver, and its highly skilled and deeply compassionate team is led by Janie Brown, a former BC Cancer Agency nurse and counselor who serves as Callanish's Executive Director. Other team members include physicians, counselors, a massage therapist, a yoga and qigong instructor, a musician and song writer, and expert cooks and nutritionists. Volunteers with professional backgrounds and/or a personal experience with cancer assist the staff. All of Callanish's programs are offered by donation or on a sliding scale.

For more information about Callanish and its programs, as well as the film, "I'm Still Here," see the website at: www.callanish.org



The Brew Creek Centre, site of Callanish retreats.



Callanish creates a healing space for people who have been irrevocably changed by cancer.

It inspires those who are living with and/or dying from cancer to reconnect with the essentials of life—and in doing so, to feel soothed, strengthened and restored. At the heart of Callanish is a wedding retreat that provides a gentle catalyst for revitalizing the spirit. After more than 20 years and over 75 retreats, Callanish has evolved into a far-reaching community deeply rooted in the fundamentals of what it means to be human.

The film "I'm Still Here" is one of many ways to become acquainted with our work.



THE FILM

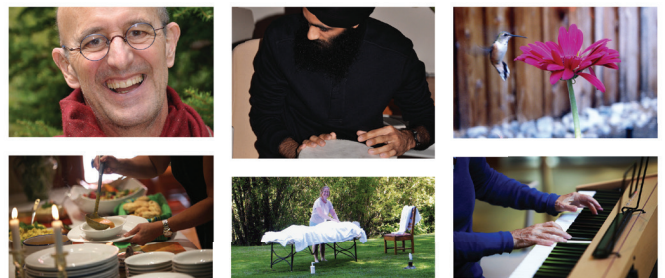
I'm Still Here: Young Adults Living Life with Recurrent Cancer

"I'm Still Here" is a short film that follows six younger-adult participants on a three-day Callanish retreat, as they are supported by a team of compassionate professionals who guide them through a healing process. The film captures participants' authentic voices and resilience in the moment, while interweaving program descriptions and reflections from staff and volunteers. While it shows a retreat specifically for younger adults, it introduces the staff, location and style of program experienced at all Callanish retreats, providing a glimpse into the heart of what we do.

DVD copies can be purchased for \$20 plus shipping. Contact us for details.



Click on the image to watch the film (15 min).



Editions of *Headlines* are also available as a pdf download on our website at: www.bccancer.bc.ca/health-info/types-of-cancer/brain-central-nervous-system/headlines

If you would like to submit an article, ask a question, or serve on our patient and family editorial board, please contact Rosemary Cashman at rcashman@bccancer.bc.ca or 604 877 6072 (phone) 604 877 6180 (fax).

All content by Rosemary Cashman unless otherwise specified.