

Headlines

Summer 12

A newsletter for brain tumour patients and their families

MEDICAL UPDATE

ASCO 2012

THIS YEAR'S MEETING of the American Society of Clinical Oncology (ASCO), the largest annual international oncology meeting, took place in Chicago in June <http://chicago2012.asco.org>. Unlike some past meetings in which there were no significant advances in brain cancer care to report, this year's meeting presented important findings from several studies with critical implications for the management of brain tumours.



The biggest hooplah surrounded treatment of anaplastic oligodendrogliomas (grade 3 tumours). Two clinical trials that were started in the mid-1990's finally had enough data to present findings, over 15 years after the studies closed enrollment. These two presentations were the highlight of the sessions, and one was honoured with an ASCO plenary session, designated for presentations deemed most significant for patient treatment.

Dr. Greg Cairncross, a celebrated Canadian neuro-oncologist, presented the data for the NCIC CE2/ RTOG 94-02 study comparing radiotherapy alone to radiotherapy plus chemotherapy for anaplastic oligodendrogliomas. When findings were originally presented in 2006, this trial was a "negative trial," meaning there was no difference in

survival between the two treatment groups. However it was noted in 2006 that not enough time had elapsed to be able to determine the average survival of all patients enrolled in the study.

By 2012 those results were known.

Oligodendrogliomas are characterized by specific genetic features involving either the loss or the retention of genetic material at chromosomes 1 and 19. In the anaplastic oligodendrogliomas *without* chromosome loss (in other words, *with* chromosome retention) at 1 and 19, adding chemotherapy to radiotherapy was not associated with

better survival. This is considered the unfavourable prognosis group. However in the tumours with chromosome 1 and 19 loss (that is, with chromosome 1 and 19 co-deletion, the favourable group), there was a 7 year difference in average survival for the patients who received chemotherapy plus radiotherapy!

Next, Dr. Martin van den Bent from the Netherlands presented the data from a similar study, the EORTC 26951 trial, which again compared radiotherapy alone to radiotherapy and chemotherapy in anaplastic oligodendrogliomas. Again this was a negative trial in 2006, but in 2012 updated data yielded results. In this

trial, once again a difference in survival was noted for patients with 1p/19q "co-deleted" tumours (the favourable group) with an average of 4 years additional survival for patients who received the radiotherapy and chemotherapy. To clarify,

the "p" refers to the short arm of chromosome 1 and the "q" refers to the long arm of chromosome 19.

So what had originally been two negative trials, thanks to long enough follow-up, are now showing that adding chemotherapy to radiotherapy will clearly benefit patients with anaplastic oligodendrogliomas if their tumours have the

favourable 1p/19q co-deletion.

The other interesting paper involved the treatment of older patients with glioblastoma multiforme (GBM). Two years previously at ASCO, the NOA-08 trial was presented comparing radiotherapy alone to chemotherapy (temozolomide) alone in patients over age 65 with GBM. The results suggested no difference between the two treatment arms of the trial. At ASCO 2012 the trial results were updated with correlation to MGMT methylation status of the tumour. MGMT is an enzyme that produces resistance to temozolomide. MGMT methylated tumours respond much



By Dr. Brian Thiessen,
Neuro-oncologist

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Q My husband has been diagnosed with a grade 4 brain tumour and is receiving radiation and chemotherapy. We're interested in doing everything we can to make sure he is longterm survivor, and we know some people are. How can we get information about clinical trials for this disease and anything else we can do to make sure he does well? Is there a special diet he should follow, or herbal treatments? Just point us in the right direction and we'll do the research.

A You and your husband naturally have many questions and concerns about his treatment and about doing well while living with a brain tumour, but it can be challenging to know what questions to ask and where to seek reliable information that will be the right fit for you and your family.

The BC Cancer Agency offers two excellent places to start researching your topics of concern: the **BCCA Library** and the **BCCA Website**. Whether or not you use the Internet, the Librarians at each BCCA Centre can help you navigate the wide variety of cancer information resources by guiding you to reliable information on specific topics and helping you with strategies to find more detailed or technical information.

Getting started is as easy as visiting or calling one of our five Libraries at the BCCA Centres in Vancouver, Victoria, Surrey, Abbotsford, and Kelowna. For weekday hours and telephone numbers, call the main number for your BCCA Centre or check the Library webpage at www.bccancer.bc.ca/Library. You can also always call our main Library in Vancouver at **604 675 8001** or toll-free in BC and the Yukon at **1 888 675 8001, ext. 8001** to have a Librarian help you. If you reach our voicemail, please leave a message and phone number so that we can return your call.

On the **Library webpage** you will see our online **Catalogue** where you can look up titles, authors, and subjects to find books, videos and relaxation CDs to borrow. The loan period is four weeks, and you may borrow items in person or, if you are unable to visit a library, you may request to borrow by mail. To do this, search the Catalogue and mark your selections. Then simply view your selection list, fill out the online form, and send the your request. The main Library receives it by email, lends the items by Canada Post, and includes a mailing label for free return.

The webpage also feature several special resource lists. **New Books and Resources** lists our monthly additions. **Popular Topics** lists recommended books, videos, and pamphlets on brain tumours and concerns such as children, nutrition, and sexuality **Library Pathfinders** are handy descriptive lists of books, dvds, websites, and support services on a growing number of topics including **Brain Cancer, Caregiving, Coping, Meditation and Mindfulness**, and more.

The extensive list of **Recommended Websites** offers a wealth of cancer and health websites that have been evaluated by BCCA librarians and professional staff. To read a bit more about how the BCCA Library can assist you, see the article in the Winter 2011 issue of the **Headlines**

newsletter available in the Libraries or on the BCCA website at Coping with Cancer > Pamphlets & Handouts > Brain.

The main BCCA Website at www.bccancer.bc.ca is available from your home or local public library at any time of the day or night, of course. If you are already reading this article on the web, you can click on the highlighted links to explore topics of interest. You will find several specific sections of the website, in addition the Library page, really useful for the many common concerns that patients, family members and caregivers may have. Clicking on **Patient/Public Info** on the homepage reveals a quick overview of topics and easy access right into some of the most useful sections. BCCA health professionals from several departments have provided detailed information on types of cancer, treatments, coping, life after cancer, and much more. For example, online **Videos** include patient education videos and online courses produced by BCCA, and many are also available on DVD to be borrowed from BCCA Libraries.

Starting with the Types of Cancer section on the **Brain and Central Nervous System**, you can find a good base of information and then follow the handy links to topics such as Radiotherapy (radiation therapy), Coping with Cancer, Clinical Trials Research, Follow-up after treatment, Survivorship, and Recommended Websites on brain tumours and on staying healthy after treatment.

The section on **Coping with Cancer** provides valuable supportive information covering a range of topics relating to emotions, family and children, support groups, nutrition, symptoms and side effects such as fatigue, and practical matters such as finances. You will also find BCCA's **online pamphlets and handouts** on brain tumours, nutrition, drugs and chemotherapy, and radiation therapy.

Question + answer



Our dynamic librarians, from left to right:
Dolly Thandi, Krista Clement, Beth Morrison, Cathy Rayment,
Harjinder Cooner, Diana Hall, Lorraine Leitz (absent, Pamela Dent)

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The Patient and Family Advisory Council (PFAC)

A FUNDAMENTAL GOAL of BrainCare BC and the BC Cancer Agency neuro-oncology program is to improve access to care and the quality of care of people with brain tumours by learning directly from the experiences of patients and their family members. A Patient and Family Advisory Council (PFAC) has been developed in an effort to meet this objective. PFAC meets 6-8 times per year to discuss care initiatives and to provide feedback to the neuro-oncology health care professionals. The council members are patients and family caregivers who have been affected by the diagnosis of a brain tumour. I am honoured to be a member of this amazing group

of people who are guiding the important work of the BrainCare BC team. As a caregiver to my husband Greg, who was diagnosed with a brain tumour several years ago, I witnessed how the medical system is often geared towards the needs of medical professionals. As a member of PFAC I can contribute to BrainCare BC's mandate to make the system more responsive to the needs of patients and their families.

PFAC is guided by the desire to ensure that all British Columbians affected by brain tumours receive timely, appropriate, optimal treatment and supportive care from the time of the initial diagnosis. PFAC members "dream big" about the

best possible care and treatment for brain tumour patients and families, and seek to identify current gaps in treatment. We advocate for improvement along the entire continuum of care from initial diagnosis to community support, and attempt to maintain and strengthen links between community, provincial, national and international brain tumour organizations and programs.

Some of the initiatives that PFAC has worked on include:

- Providing advice about the development of new patient information and support
- Offering suggestions about the format of brain tumour support group meetings
- Guiding the structure and content of BrainCare BC's website
- Reviewing different online supports for persons living with brain tumours,
- Creating an annual award to recognize individuals (patients and family caregivers) who make outstanding contributions to the brain tumour community
- Developing the program for the 2012 Brain Tumour Information Day.

The group has also provided input into clinical research projects focused on family and caregiver supports, such as a peer navigator program in which "veteran" patients meet with new patients to offer support and share their experiences. PFAC has supported the creation of a video resource for oncologists and health providers, in which a patient offers her perspective and provides advice to doctors caring for brain tumour patients.

In the coming year PFAC plans to build on initial successes towards our goal of compassionate, responsive, patient-centred care for all individuals living with a brain tumour diagnosis. If you would like to learn more about PFAC, please contact Rosemary Cashman.

By Nancy Pye

Question + answer

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Complementary Therapies highlights the **CAMEO** Program, a research project that can help people living with cancer find evidence-based information and make decisions about complementary and alternative therapies such as herbal treatments. On the Research section of the BCCA homepage, **Clinical Trials Research** provides an online pamphlet, a video, answers to important questions to consider, and lists of the BCCA clinical trials that are currently open.

You will find further useful resources on all these topics and many more on the list of **Recommended Websites** that we have evaluated. **Brain and CNS** offers several excellent Canadian and U.S. sites, including the **Brain Tumour Foundation of Canada**. If you don't already have your own copy of the BTFC's **Brain Tumour Patient's Handbook**, you may wish to request one

from them or borrow a copy from the Library. **Clinical Trials** provides several resources for identifying trials in Canada, the U.S., and internationally. A good place to start is **Canadian Cancer Trials**.

Browse the Recommended Websites to explore the full range of topics such as Coping with Cancer, Caregivers, Chat Rooms, Clinical Trials, Complementary Therapies, Exercise, Nutrition, Survivorship, Young Adults with Cancer, Advance Directives/Advance Care Planning, Dictionaries, and Images.

Remember, wherever you are in BC or the Yukon, the BCCA Library and Website can help "point you in the right direction" for the information you need! We especially invite anyone who attends the Brain Tumour Information Day in October to drop by the Vancouver Centre Library which will be right next door.

By Diana Hall, BCCA Librarian

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 Sharon Kennedy at the BC Cancer Foundation, 604 877 6160 or 1 888 906 2873 or skennedy@bccancer.bc.ca

Brain Tumour Information Day

Saturday, October 13, 2012 at the BC Cancer Research Centre
675 West 10th Avenue, Vancouver BC (across the street from the BC Cancer Agency)

Program

8:30 to 9:00 a.m. Coffee and Registration	11:20 a.m. to 12:15 p.m. <i>Concurrent Sessions</i> Support Group Sessions – To be confirmed Relaxation Therapy – Sarah Sample or Library Session – BCCA Librarian
9:00 to 9:15 a.m. Opening Remarks – Yaron Butterfield	12:15 to 1:15 p.m. Lunch
9:15 to 10:00 a.m. Brain Tumour Basics Dr. Brian Thiessen	1:15 to 2:00 Patient and Caregiver Panel
10:00 to 10:35 a.m. Surgery and Brain Function To be confirmed	2:00 to 2:30 p.m. <i>Concurrent Sessions</i> Seizure Management – Dr. Rebecca Harrison or Return to Work or School – Maureen Parkinson
10:35 to 10:50 a.m. Refreshments	2:30 to 3:00 p.m. Complementary Therapies – Dr. Lynda Balneaves
10:50 to 11:20 a.m. Radiotherapy for Brain Tumours Dr. Allison Chew	3:00 to 3:15 p.m. Closing Remarks

There is no cost to attend, but **you must register** so that we can order your **delicious refreshments**:

To register: Contact **Colleen Pelletier 604 877 6000 x 2418** or cpelleti@bccancer.bc.ca by October 1, 2012.

Please provide:

- Your name
- Number of people attending
- Your address or email AND phone number
- How did you hear about the conference?
- Do you plan to attend full day ___ morning session only ___ afternoon session only ___?
- Do you plan to stay for lunch (vegetarian and non-vegetarian options available)?



Register Now, Space is Limited!

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

ASCO 2012

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better to chemotherapy since their MGMT levels are very low. In this trial, patients whose tumours were MGMT methylated did better with temozolomide compared to radiotherapy, whereas unmethylated tumours did better with radiotherapy compared to temozolomide. This was the first time MGMT methylation could accurately predict which treatment might be better for individual patients.

Currently at BCCA we are running a trial for older patients with GBM looking at combining temozolomide with radiotherapy and it will be very interesting to see if the MGMT status has a similar impact in determining which patients do better.

Overall, this year's ASCO conference was an exciting meeting with some very impactful research findings. On the new treatments front, studies were presented, but unfortunately there was no new therapy that seemed particularly promising. Vaccine trials seem to be catching on in various places, but larger trials are still needed to determine the precise role of vaccine therapies in brain tumours. Bevacizumab (Avastin®) still seems to be the hot drug for patients with relapsed malignant gliomas, but finding good drugs to combine with it has been problematic. At present, no particular drug plus bevacizumab stands out as an improvement over bevacizumab alone.

For more information about ASCO updates, see *Headlines Summer 2008*, *Summer 2010* and *Summer 2011*. For information about oligodrogliomas, see *Fall 2006*, *Summer 2009*, *Summer 2010* and *Fall 2011*. For information about glioblastomas, see *Spring 2006*, *Summer 2009*, *Winter 2010* and *Summer 2010*.

www.bccancer.bc.ca/PPI/copingwithcancer/pamphlets/brain.htm

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 6180 (fax).

All content by Rosemary Cashman unless otherwise specified.