

Headlines

Spring 12

A newsletter for brain tumour patients and their families

MEDICAL UPDATE

Clinical trials for brain tumour patients

AT PRESENT TWO CLINICAL TRIALS are open at the BC Cancer Agency for brain tumour patients, and a third will open shortly. All are for patients with glioblastoma, the most commonly occurring brain tumour in the adult population, and therefore the target of most clinical trials.

1. PX-866 – A phase II study for patients with glioblastoma at first recurrence (Enrolling)

Sponsor: National Cancer Institute of Canada Clinical Trials Group

This study investigates the use of a pill form of chemotherapy for patients whose tumours have grown after receiving initial treatment with chemotherapy and radiation or radiation alone. Participation in this trial requires that patients have received only initial treatment and no further therapies at relapse. They must also have been off treatment for a minimum of 28 days before starting the PX-866. This drug was found to have anti-tumour activity in phase I trials, and interim analysis of the phase II study also showed a therapeutic effect for some patients. PX-866 is taken daily as a capsule with water and each cycle is 8 weeks long. Potential side effects include diarrhea, nausea, vomiting and fatigue.

2. CE.6 – A randomized phase III study for newly diagnosed glioblastoma patients who are 65 years or older (Enrolling)

Sponsor: National Cancer Institute of Canada Clinical Trials Group

Age is known to be an important predictor of outcome for patients with glioblastoma, and older patients do not tolerate or respond as well to treatment as younger patients with this disease. As a result, older individuals (those who are more than 65 years old) often receive radiotherapy alone if they are well enough to receive any treatment at all. However, there is evidence to suggest that the use of temozolomide chemotherapy with radiotherapy may be beneficial for some patients. This study capitalizes on the significantly improved outcomes shown with the use of concurrent chemotherapy and radiation for this disease, but modifies the dose of the radiotherapy in order to make it more tolerable for older patients. There are two treatment arms and a computer assigns each patient to receive either 1) short course (three weeks) of radiotherapy alone or 2) short course (three weeks) of radiotherapy combined with daily temozolomide followed by adjuvant cycles of temozolomide chemotherapy until disease progression.

3. A phase III international, randomized, double-blind controlled study of rindopepimut /GM-CSF with adjuvant temozolomide for patients with newly diagnosed EGFRvIII positive glioblastoma (Will open soon)

Sponsor: Celldex Therapeutics

Cancer is supported by certain cellular processes which foster the growth of tumour cells. The epidermal growth factor receptor (EGFR) is a protein found on the surface of cells and is involved in the control of cell growth and division. A mutated variant of this receptor, EGFRvIII, is present in over one third of glioblastoma tumours and is associated with particularly aggressive tumours. This study assesses the effectiveness of a vaccine called rindopepimut which is directed against EGFRvIII. The vaccine is administered to patients with confirmed EGFRvIII positive glioblastoma. Administration begins after completion of combination chemotherapy and radiotherapy, the standard treatments for this disease. The goal of vaccine therapy is to prompt an immune response, that is, to help the body fight the cancer. EGFRvIII is only present on the tumour cells and not on healthy brain cells. This makes it an excellent target for vaccine therapy as it allows the vaccine to direct the immune attack only against the cancer cells, and does not affect the normal brain cells. The vaccine has been quite well tolerated in early trials but may cause some skin reactions at the site of the injection, as well as fatigue.

For more information about clinical trials for brain tumour, see Headlines Spring 2007, Spring 2010 and Summer 2010.

Understanding Clinical Trials

CLINICAL TRIALS ARE research studies involving human subjects. The purpose of a clinical trial for cancer patients is to identify effective new treatments for a disease, to test the safety of experimental treatments, and to determine whether they are more effective than the usual treatment for the disease in question.

Your decision to participate in a clinical trial is a personal one. Extensive research is performed on experimental treatments before they can be approved for use in humans, however there may be undiscovered risks that only come to light with a well designed clinical trial. A benefit of participation could be that you, or other patients, will receive a better treatment for your disease.

Your oncologist and clinical trial nurse will describe potential risks and benefits of participation in the clinical trial as well as possible so that you can make an informed decision about what is best for you.

Some terms to know:

Phases of trials

Phase I Researchers test an experimental drug or treatment in a small group for the first time to evaluate its safety, determine

a safe dosage range, and identify side effects.

Phase II The experimental study drug or treatment is given to a larger group of people to see if it is effective and to further evaluate its safety.

Phase III The experimental study drug or treatment is given to larger groups of people to confirm its effectiveness, monitor side effects, compare it to standard treatments, and collect information that will allow it to be used safely.

Phase IV Further information is collected regarding the drug's risks, benefits, and optimal use.

Randomized controlled clinical trial

A computer determines the treatment each study participant receives. This ensures that there is no bias in the selection of treatment and that every participant has the same chance of being selected for either the experimental treatment arm (the treatment under investigation) or the standard treatment arm (the usual treatment given for a disease, to which the experimental treatment is being compared). At the end of the trial, the treatment assignments are revealed and researchers can identify

whether the experimental treatment was more effective than the standard treatment, and also can compare the side effects of each treatment.

Double-blind clinical trial

In a double-blind trial, neither you nor your oncologist will know whether you are receiving the experimental or standard treatment. Again, this ensures that every study participant receives the same care throughout the study. At the end of the trial, the study is "unblinded" and it is revealed which treatment was received by each participant.

Placebo

A placebo is a substance that is given in place of the experimental treatment, but in fact has no active ingredients. For example, patients in the standard treatment arm of a placebo-controlled clinical trial would receive a harmless sugar pill, while patients in the experimental treatment arm would receive a pill containing the medication under investigation. This helps to ensure that both treatment arms look the same and neither patients nor the oncologist will know which treatment a participant is receiving. Of course if a patient truly needs active treatment, a placebo alone would not be given. It might be given in addition to a standard treatment, to see if the combination of the experimental treatment with the standard treatment is more effective than the standard treatment alone.

For more information on understanding clinical trials, see Clinical Trials Research on the [BCCA website at www.bccancer.bc.ca/RES/ClinTrials/default.htm](http://www.bccancer.bc.ca/RES/ClinTrials/default.htm).



For more information about clinical trials for brain tumour, see *Headlines* Spring 2007, Spring 2010 and Summer 2010.

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).

All content by Rosemary Cashman unless otherwise specified.

Brain Tumour Support Groups, BC Cancer Agency

Have you ever wondered:

- How other patients and families manage the stress of a brain tumour diagnosis?
- Whether other people have experienced some of the problems you're having, and how they've managed these problems?
- What helped someone else get through a particularly tough emotional time?
- How others found their "new normal" after treatment?

You might consider attending a support group. Here are some comments made by participants of brain tumour support groups

"I feel normal there. I'm so used to feeling that I'm not normal, so it's a relief to come to support group."

"There is such positive energy in the group."

"The group is a place of healing for me."

"Everyone cares about each other. I try to offer as much support and help as I can, and I receive the same in return."

Contact the group facilitators below for more information, or contact your BC Cancer Agency Patient Family Counselling Office.

Kelowna

3rd Monday of each month 11:00 am to 12:30 pm
Facilitator: Valery Colquhoun (250) 712 3971

Vancouver

1st Wednesday of each month 9:30 to 11:00 am
AND

3rd Thursday of every second month (i.e. May, July, September, November in 2012) 6:30 to 8:00 pm

Facilitators: Ira Yakubovitz, Douglas Ozier and Rosemary Cashman
604 877 6000 x 2813, 604 877 6000 x 2185 or 604 877 6072
Every other morning session is a split support group: one for patients, one for caregivers.

Victoria

2nd Thursday of each month 11:00 am to 12:30 pm
Facilitator: Catherine Traer-Martinez (250) 519 5528



SPRING
sprint
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Spring Sprint 2012

To benefit the Brain Tumour Foundation of Canada

The goal of the 2012 Spring Sprint is to raise \$1.6 million for brain tumour research and patient support and information programs. There are 20 events across Canada, kicking off with the London Spring Sprint on April 21, 2012. Register today and raise funds online, or hold a fundraiser. Walk/run with your friends, family and co workers! Put together a team and have even more fun!

Where: Vancouver
Burnaby Lake, Rugby Club
3760 Sperling Avenue
When: Sunday May 27
Registration: 10 am
Start: 11 am
Distance: 2.5 or 5 km walk or fun run

Where: Victoria
Cedar Hill Recreation Centre
3220 Cedar Hill Road
When: Sunday May 27
Registration: 9:30 am
Start: 11 am
Distance: 3.5 km walk or fun run

For more information
www.braintumour.ca/627/spring-sprint

Sharon Whiteside
National Special Events Manager
swhiteside@braintumour.ca
1 800 265 5106 or
519 642 7755 ext 229

Q I have recently been diagnosed with a grade 4 brain tumour. I am going to start chemo and radiation very soon. I have 3 children ages 6, 12 and 15. My 15 year old hasn't been easy to raise in the best of times and he is acting out now. My ex and I have not had a very good relationship since we split up 3 years ago. My sister, brother and devastated parents live in Ontario and I am feeling completely overwhelmed, but my biggest fear is for my children. What do I tell them, how do I help them? I know this is a bad disease, and I have not given up hope, but I also worry about what will happen to them.

A Thank you for sharing this important question. Your concerns are valid and your children will definitely need help in coping with your diagnosis. Remember that the known is often less scary than the unknown, so prepare your children in a manner that takes into account their ages, their cognitive and emotional maturity, and their unique personalities. By adopting a flexible and open approach, you can guide your children over time towards an understanding of what is happening to you and your family. You can acknowledge the sense of uncertainty and introduce healthy ways of dealing with feelings and changes. By encouraging your children to express their concerns and feelings, you may ward off misinterpretation and will also be able to respond quickly to calm their fears whenever possible.

Regardless of age, all children should be reassured that they did nothing to cause the tumour. A good rule of thumb when talking with your children is to let them take the lead in terms of indicating how much or how little they want to know. Find out what is really concerning them. Avoid providing too much unnecessary detail or speculation, but be honest in your conversation.

Children may imagine the worst, and it is important for you to be ready for

questions about death. Many parents worry about crying in front of their children, but it is okay to cry sometimes. By crying or showing sadness, you are modeling that emotions are a part of the journey.

It is often helpful for children to maintain their regular routines as much as possible (for example, to continue with school and social activities) in order to provide them with a familiar structure during this time of stress and transition. It is not uncommon for children to temporarily demonstrate regressive behaviour, or to act out when coping with a crisis. No one should have to face such a challenging situation on his or her own. The counsellors at your children's schools and your health care team can offer further support and guidance for you and your children.

The BC Cancer Agency offers the online resource *Cancer in my Family* for children ages 8 to 12 to learn about cancer and to explore their feelings. There is also a Children's Club Program for children 5 to 12 years old. This combines art therapy and support groups for children and their parents and is offered at Vancouver, Abbotsford and Fraser Valley Centres. For parents, *Reaching Out to Your Children When Cancer Comes to Your Family: A Guide for Parents* at www.cancerinmyfamily.ca/parent-resources.aspx provides guidelines for talking to children of different ages, whose parents are at various stages of treatment.

Here are some general tips for talking to your children about your diagnosis and treatment. More can be found at *Cancer and the Family* on the BC Cancer Agency Coping with Cancer webpage www.bccancer.bc.ca/PPI/copingwithcancer/emotional/family.

- Remember that your children's

individual needs might differ depending on their age and personality.

- Have the conversation as soon as you are able and when you can be clear about what you want to share.
- Remember that it doesn't have to be one big conversation. You can support and reassure your children that the initial conversation is the first of many.
- If you feel unable to talk to your children, select someone who can, and be present during that conversation.
- You may find it helpful to write down what you wish to say.
- As a parent, you cannot protect your children from worry, but you can help to ease their anxieties by giving them accurate information and talking with them about their fears and worries.
- Remember to give your children time to adjust and encourage them to be involved in their regular activities.
- Provide opportunities for them to come back and ask questions or share their feelings.
- Let your children know:
 - A brain tumour is no one's fault, and you cannot "catch" it from someone who has one.
 - They will be looked after no matter what.

For children 13 and over, two websites provide information and resources for teenagers.

- www.riprap.org.uk (British site)
- www.cancer.gov/cancertopics/coping/when-your-parent-has-cancer/page2 (American site. You can download or order a free booklet).

For more information, speak to your health care team, see *Coping with Cancer* at www.bccancer.bc.ca/PPI/copingwithcancer, visit your friendly BCCA librarian for other resources, or see www.bccancer.bc.ca/PPI/Library/default.htm.

*By Ira Yakubovitz, MSW, RSW
Registered Social Worker*

Question + answer



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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