



**Kidney
Cancer
Canada**



Newsletter

June 2008

Patient Support and Advocacy Group for Canadian kidney cancer patients and their families.

Kidney Cancer Facts

- In 2006, approximately 4600 new cases of kidney cancer were diagnosed in Canada.
- Kidney cancer occurs approximately twice as often in males as females.
- Renal cell carcinoma (rcc) is the most common form of kidney cancer (90%) but there are also many other types such as transitional cell carcinoma, Wilm's tumor (childhood kidney cancer) and renal sarcomas.
- Kidney cancer is considered a rare disease (affects less than 1/2000)
- Kidney cancer is often difficult to detect and therefore can go untreated for many years.
- Some symptoms may include but are not limited to: blood in the urine, abdominal mass, back pain, weight loss, anemia, symptoms of metastases, fever, high calcium or high blood counts



Canadian kidney cancer specialists, patients and caregivers met this past winter for a three-day meeting to achieve three important objectives for patients and researchers in Canada:

1. Achieve consensus among expert professionals and survivors on the management of kidney cancer in Canada and develop National Guidelines
2. Stimulate clinical research in kidney cancer - including opportunities for national and international collaboration - and define educational needs to improve kidney cancer care in Canada
3. Initiate a process for developing a Cancer Control Strategy for kidney cancer to ensure all Canadians have equal access to care.

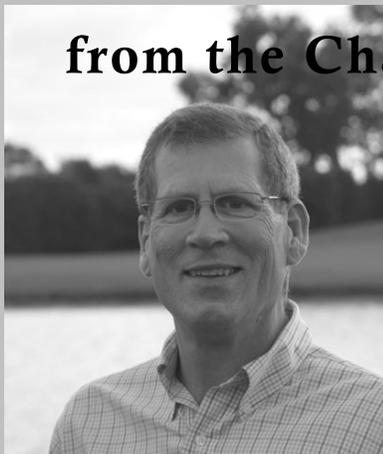
Proposed guidelines for rcc care in Canada were published by the Canadian Urological Association in the June 2008 issue of the CUA Journal and are posted on our website.

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Message

from the Chair



Looking back to our roots as four kidney cancer patients sitting together in a clinic waiting room, I am both astounded and delighted to see how everyone has come together to develop a truly national, truly Canadian, patient led support and advocacy organization.

In January of this year, Deb Maskens, our Vice Chair and I were pleased to represent so many patients at the first ever Canadian Kidney Cancer Forum at Mt. Tremblant Quebec. There we met with 75 renal cell carcinoma specialists who wholeheartedly endorsed our efforts as a patient group. We cannot thank them enough for their support and guidance and look forward to another national meeting in 2009 that will include the patient community.

Since January, we have been delighted to watch our Board of Directors grow nationally. We have added Directors from British Columbia, Alberta, New Brunswick, and are very excited to have the additional support of our first part-time Executive Director, Tammy Udall.

As you know so well, kidney cancer is a difficult disease and we are all fighting and supporting each other together. Sadly we lost two of our founding four members early this year. Don Kurylo and Paul Beregi were two of the four who first said "we need to have a group". Don and Paul, this group is your legacy and we are all so thankful for what you have helped to build for patients right across Canada.

Lastly, I want to take a moment to thank everyone who has played a role in helping us build Kidney Cancer Canada. We have been generously supported by individual donations and by our three founding sponsors Bayer Healthcare, Pfizer Canada, and Wyeth Canada. We would not be where we are today without all of you – sponsors, physicians, nurses, caregivers, volunteers and most of all, our fellow patients who teach and inspire us with their courage and determination.

As we say, Onwards!

Tony Clark

What can you do to help?

Volunteer

KCC requires volunteers and patient advocates in every province.

If interested or to learn more about volunteer opportunities please call

1-866-598-7166

or send an email to

info@kidneycancercanada.org

Tell Your Story

Are you facing treatment challenges since being diagnosed with renal cell carcinoma?

- Write a letter to your local MPP or Provincial / Federal Health Minister
- Write an editorial to your local paper
- Or contact KCC - We might be able to use your story on our website or in a future newsletter.

KCC can help you write your story.

Update on Treatment Access for RCC

Written by
Deb Maskens, Vice-chair

A year ago, Canadian kidney cancer patients and their families first started rallying together to ensure that the first approved drug for rcc in over 10 years would be funded by our provincial governments. Despite an initial negative response from the Common Drug Review in Ottawa, **Nexavar** eventually went on to be funded by most provincial drug programs (with notable exceptions in Quebec and Prince Edward Island).

We are pleased to report that, despite some lengthy delays in some provinces, **Sutent** is now funded to some degree in every province except Prince Edward Island. Many of you wrote letters, visited your MLA/MPP, and participated in our advocacy efforts. Without raising your voices as patients and family members, kidney cancer would not have received the attention it has with decision makers over this past year. Thank you all.

Still, we are painfully aware that there are gaps in the various provincial plans. Some patients who do not qualify by age or income level are still paying for their cancer treatment entirely out of pocket. Others with rarer subtypes of rcc often find themselves completely without public drug coverage due to lack of

clinical trial data specific to that rare subtype.

We have work yet to do. On December 21st 2007, the third treatment for rcc (**Torisel**) was approved by Health Canada. We are now anxiously awaiting news from the Joint Oncology Drug Review (JODR) to learn whether this important new option will be recommended for provincial reimbursement.

In the months ahead, we look forward to seeing a fourth treatment option (**RAD001/Everolimus**) submitted to Health Canada for rapid review.

At Kidney Cancer Canada, our position is that kidney cancer patients need not just one option, but every available treatment option to help oncologists and patients manage kidney cancer as a chronic disease. We know that there is emerging research evidence that indicates these treatments can work effectively as sequential treatments – significantly extending the lives of patients with this disease, and offering them real hope.

Updates on new treatments are regularly posted on our website. In particular, check out **ASCO 2008 Research Updates** where we list exciting news about new treatments, treatment combinations, and proof of extended survival for patients with renal cell carcinoma.

Location, location, location...

It really does matter what province you live in especially when you have Kidney Cancer

Written by Pat Mein-Shields, Patient

Often we hear that the right location when choosing where you will live is of utmost importance. But who would believe that it is even more important in choosing the right province, especially when it comes to getting drug coverage. Canadians who have been diagnosed with kidney cancer (or renal cell carcinoma) are finding that it does depend on which province you live in.

As an example of this inequality in coverage, take Prince Edward Island. According to Jim Day, a

reporter for the Charlottetown Guardian, "Islanders have the poorest access to publicly-funded medications in Canada." With a backlog of about 70 drugs waiting for approval by one or more of three expert advisory committees, the province is falling even farther behind with the newest medications that can help save or extend people's lives.

A recent letter to the editor in the Charlottetown Guardian brings this point home. Written by Annie van der Kaay, it is an attempt to

inform residents of P.E.I. of the plight that her husband, Hannie, is facing. After being diagnosed with renal cell carcinoma, he applied to the provincial government to help with the cost of a drug that will extend his life. This drug, Sutent, costs \$7,558.42 for a 28 day supply but is an ongoing treatment that needs to be repeated every six weeks. The province turned him down.

The couple can hope that they might get accepted for compassionate coverage from a foundation working at arms' length with a drug company. They can use all their savings and sell their personal property to pay until all these monies are depleted. Or they might

have to choose to move to another province such as New Brunswick, Nova Scotia, Quebec, Ontario, Alberta or B.C. where provincial funding is available depending on rcc subtype and income. For terminally ill patients this choice comes at a time when they need all the support they can get from those same people that they might have to leave.

Location, location, location! This should not be a remote consideration for any person having to deal with kidney cancer. Full access to federally approved drugs must be available to all Canadians, no matter whom you are or where you live.

UPCOMING DATES

⇒ National Webcasts and Patient Meetings - Toronto

June 12

Stress, Nutrition & Moving Forward

September 17

Understanding Your Pathology

November 27

Managing the Emotional Side Effects of Kidney Cancer

⇒ Montreal Patient Meeting

June 17

Dr. Tanguay and Dr. Soulieres
(meeting to be conducted in French)

⇒ Edmonton Patient Meeting

September 11

Dr. North and Dr. Ruether

⇒ Vancouver Patient Meeting

October 2008

Other Canadian locations TBA
Check the website for updates

*Attend in person
or on-line during a live webcast
(available for some meetings)*



Meet the Executive Director

Greetings everyone!

It is my pleasure to have been selected as Kidney Cancer Canada's first ever Executive Director.

I would like to take this opportunity to tell you all a little bit about myself. I have worked for ten years as a volunteer for the Canadian Cystic Fibrosis Foundation; serving two terms as President of the local chapter where I live, one term as V.P. of Publicity and Promotions and ten years as newsletter editor. Additionally, I was a founding member of a grass

roots international based meetings via live webcast.

non-profit organization which supports males born with XXYY Syndrome; a rare genetic disorder. I have also worked for the past several years with a career in fundraising, communications and volunteer development. I believe that I will be able to offer Kidney Cancer Canada a vast amount of skills and experience as we continue to build the organization nationally.

As I work alongside the Board of Directors over the next year, we will continue to increase awareness and provide support to kidney cancer patients and their families from coast to coast. We are scheduling patient support and information meetings in Quebec, Alberta, British Columbia and Ontario with plans underway for a meeting in the Maritimes. To support our goal of reaching all Canadians we are continuing to offer transmission of these

We also look forward to working with the provincial governments in securing equal access to the best possible treatment and medications no matter where in Canada our patients live. We will continue to collaborate with our partners both provincially and nationally to help them introduce novel therapies to treat Canadians with kidney cancer.

Thank you to all of the board members, medical professionals, sponsors, community partners and volunteers who have helped build this organization to make it what it is today. I am very proud to be here and very much looking forward to working with all of you in the fight against Kidney Cancer!

Kindest regards,

Tammy

Volunteer Spotlight

Karen Ross - Director, New Brunswick

David Ross was diagnosed with clear cell renal cell carcinoma in August 2000 and had a radical nephrectomy (removal of the kidney) at that time. In the fall of 2003 he experienced a recurrence in the kidney bed cavity which is normally quite rare (2 % of cases). In the spring of 2003 David went on Interferon as he was told that the tumour was inoperable. Following the advice of a urologist at the Lahey Clinic in Boston he returned to Fredericton to have a very successful resection of the kidney bed cavity. David was well for some time but in the fall of 2004 he was diagnosed with metastasis in the liver and as a result he travelled to the Beth Israel Deaconess Medical Centre in Boston, Massachusetts to receive High Dose Interleukin II treatments to which he did not respond. Since October 2005 David has been taking 37.5 mg. of Sutent (by Pfizer) every day for 4 weeks with a 3 week rest period under the supervision of Dr. Lori Wood, oncologist with a special interest in kidney cancer, at the QEII in Halifax.

In January of 2008 Karen and David Ross attended the first ever Canadian Kidney Cancer Consensus Forum. They saw first hand some of the good work



that Kidney Cancer Canada was doing and decided to get involved. Karen was delighted to be appointed as the KCC's Director for New Brunswick.

Since that time Karen has been working on increasing awareness about kidney cancer and Kidney Cancer Canada throughout New Brunswick. She has been distributing brochures and meeting announcements in the local hospital and doctors' offices in Fredericton as well as networking through the province in search of people to do the same in their area. Karen has organized a group of kidney cancer patients and caregivers to gather at the Dr. Everett Chalmers Hospital in Fredericton for the quarterly KCC Patient Information and Support Meetings broadcast live out of Toronto via webcast. This past May Karen attended the Canadian Psychosocial Oncology Partners Conference in Halifax where she did a presentation about Kidney Cancer Canada.

www.kidneycancercanada.org



Making a Difference



Employees at Pfizer contributed \$5 each to support Kidney Cancer Canada. The overall amount given to KCC was \$2,500. Thank you Pfizer.

To receive the
KCC Newsletter
& other important
updates
via email visit
the website at

www.kidneycancercanada.org

Simply visit the
KCC home page
and click on

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2008 Kidney Cancer Canada

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