



**Kidney
Cancer
Canada**



Newsletter

November 2008

Patient support and advocacy group for Canadian kidney cancer patients and their families.

Patients Urged to Join Advocacy Campaign



Cancer Care by Postal Code?

Case Example: Shown in green are the only two provinces that publicly fund Torisel
 X - Provinces that have said **no** to Torisel
 ? - Provinces that have not yet decided
 (November 2008 - see our website for updates)

Patients, caregivers, family members and friends are strongly urged to raise their voices against a climate of unfair restrictions, delays and refusals to publically fund new therapies for kidney cancer.

While Canadians rightly take pride in the Canada Health Act, many are surprised to learn that the provision of some medications to treat disease fall outside of this federal act. Each province and territory manages its own cancer drug budget and decides which drugs to make available on their respective public formularies.

Across Canada, access to treatment for kidney cancer varies widely depending upon your province of residence, if you have private health insurance, your exact type of kidney cancer, and whether you have received any prior therapies.

For example, if you live in Prince Edward Island, the Yukon, the Northwest Territories or Nunavut, new drugs that are available for the treatment of kidney cancer are not reimbursed under their public drug plans. In Ontario, the provincial drug plan excludes reimbursement for new kidney cancer drugs if you have non-clear cell renal cell carcinoma (such as papillary or chromophobe). British Columbia offers funding for Sutent, Nexavar, or

Torisel (one of the three) as a first-line therapy. In B.C., a patient needing to switch to another treatment must have private insurance or hope to be eligible for a clinical trial.

The Case for Torisel: Torisel was approved by Health Canada in December 2007 as an effective drug for metastatic renal cell carcinoma. At that time, many patients with comprehensive private insurance were able to access the drug privately.

In Sept. 2008, the Joint Oncology Drug Review (JODR), Canada's new interprovincial drug review body (involving all provinces except Quebec) made a recommendation to the provinces NOT to reimburse the cost of Torisel for those patients relying on public coverage.

With a negative recommendation from the JODR, we fear that many provinces will deny access to Torisel. To date, the only two provinces to allow limited access are Nova Scotia and British Columbia. Ontario and Quebec have denied access to date. Decisions are pending in all other provinces.

What Can You Do? Please write a letter to your elected representatives. Sample letters and addresses are available on our website at: www.kidneycancercanada.ca

Canadian Kidney Cancer (RCC) Treatment Guidelines

The treatment of rcc has changed dramatically since the advent of new targeted therapies in 2006. Patients who have questions about follow up and recommended therapies should consult the 'Management of Kidney Cancer Forum Consensus Statement' developed by leading Canadian rcc specialists.

To view the guidelines go to the Kidney Cancer Canada website *Web Resources* section and look under:

[Kidney Cancer Treatment Guidelines.](#)

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Message

from the Chair



Fellow patients, caregivers, and friends,

What a phenomenal year it has been for Kidney Cancer Canada. From our roots as four patients sitting together in a clinic waiting room in 2006, KCC has quickly grown into a national patient support and advocacy organization with members from Newfoundland to British Columbia. We are delighted that new patients continue to find our website and are connecting with other patients for support, information and encouragement.

In 2008 we had the privilege of meeting so many patients, family members and healthcare professionals at meetings across the country – and we look forward to meeting more of you in 2009.

Behind the scenes, KCC is still a very small patient-led organization that relies on the passion, dedication and ideas of our growing team of volunteers. A special thank you goes to those volunteers who have taken on additional responsibilities as Board Members. I also want to recognize the medical community and their unwavering support of our organization. We thank you all for your dedication to the best care for Canadians with kidney cancer.

Equally so, KCC is deeply grateful to our pharmaceutical sponsors who fund us with unrestricted educational grants that allow us to host patient education meetings and national webcasts.

In 2009 we have significant work ahead of us to ensure that patients across Canada have equal access to treatments for renal cell carcinoma. We are working very hard to ensure that the decision about your treatment is a decision between you and your doctor, without unnecessary restrictions placed by provincial funders. Please join us in our advocacy efforts. Even if you have never written a letter to your elected representatives before, we urge you to stand up for kidney cancer patients – for yourself, your family members, and for those who are yet to be diagnosed.

Wishing good health to you all. As we say at KCC...ONWARDS!

Tony Clark



Promising Clinical Trials in Kidney Cancer

Clinical trials offer patients the opportunity to contribute to research in kidney cancer. For many patients, a clinical trial also offers an excellent opportunity to obtain a treatment not otherwise available in their province.

Many clinical trials for kidney cancer are currently underway in various major cancer centres across Canada. To determine your eligibility for a particular clinical trial, please see one of the websites listed below or speak to your oncologist.

A small sampling of current trials follows here:

For Adjuvant Treatment:

Phase 3 ASSURE trial: Nexavar versus Sutent versus placebo. Patients must be at a maximum of 12 weeks post-nephrectomy with no evidence of disease.

For First-line Treatment:

Pazopanib versus Sunitinib in the treatment of locally advanced and/or metastatic renal cell carcinoma (Phase 3 trial)

For Second-line Treatment:

- Axitinib (Ag 013736) as second-line therapy for metastatic renal cell cancer. Axitinib versus Sorafenib (Nexavar)
- Torisel versus Nexavar (as second-line therapy post Sutent)
- RAD001/Everolimus (Afinitor) – Expanded Access Program for post Sutent or Nexavar (or both)
- ABT-869 (as second-line therapy post Sutent). Phase II trial.

U.S. studies:

Papillary RCC: Phase II study of GSK1363089 (Formerly XL880) for papillary renal cell carcinoma (PRCC)

Helpful Websites for Researching Clinical Trials

www.clinicaltrials.gov

(U.S. based site. Includes Canadian sites.)

Each province may also have their own website for clinical trials. For example, Ontario patients can access:

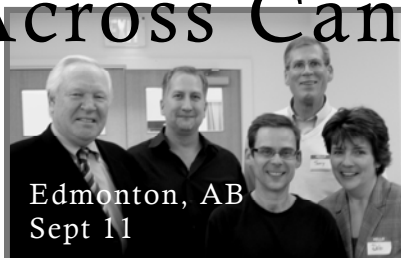
www.ontariocancertrials.ca

Patient Meetings Across Canada

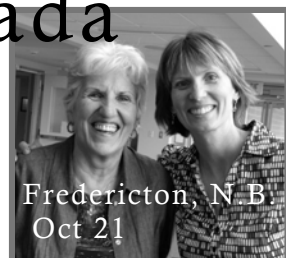
Over the past several months Kidney Cancer Canada has had the opportunity to host meetings in several Canadian cities.

- Our first French patient meeting took place June 17 in Montréal, Québec. The meeting featured two experts, Dr. Simon Tanguay and Dr. Denis Soulières, who spoke on 'Recent Developments in the Management of Kidney Cancer'.
- On Sept. 11 KCC hosted its first patient meeting in Edmonton, Alberta with guest speakers Dr. Dean Ruether from the Tom Baker Cancer Centre in Calgary and Dr. Scott North from the Cross Cancer Institute in Edmonton.
- Cancer Care Manitoba organized a patient support meeting on Sept. 25th. KCC was proud to sponsor this very successful meeting where over 100 people attended either in person or via the Telehealth Network.
- Kidney Cancer Canada hosted a meeting and televideo presentation for medical professionals in Atlantic Canada on Oct. 21. Dr. Lori Wood of the QEII Health Sciences Centre in Nova Scotia flew to Fredericton, N.B. to present "Recent Advances in the Treatment of Kidney Cancer".
- Dr. Christian Kollmannsberger and Dr. Peter Black were guest speakers at the first ever KCC patient meeting in Vancouver, B.C. which took place on Oct. 30.

Many of these meetings have been video recorded and put on the KCC website. You can access these videos by visiting the 'Our Meetings' section of the Kidney Cancer Canada website. Please note that you will need to *login* to view these meetings. If you are not already a KCC member you will need to register yourself. Please visit the KCC homepage and click on Join KCC to register.



Edmonton, AB
Sept 11



Fredericton, N.B.
Oct 21



Winnipeg, MB
Sept 25



Montréal, QC
June 12



Vancouver,
October 30



B.C.

Top Left: Dave Chatters, KCC Director for Alberta, Dr. Dean Ruether, Dr. Scott North, Tony Clark, KCC Chair & Deb Maskens, KCC Vice-chair; **Top Right:** Karen Ross, KCC Director for N.B. and Dr. Lori Wood; **2nd Row Left:** Dr. Darryl Drachenberg & Dr. Piotr Czaykowski; **2nd Row Right:** Lori Stewart, Cancer Care Manitoba and Tony Clark; **3rd Row Left:** Dr. Denis Soulières; **3rd Row Right:** Dr. Simon Tanguay; **Bottom Left:** Evelyn Hazenberg and Ian Hazenberg, KCC Director for B.C.; **Bottom Right:** Dr. Peter Black, Tony Clark, Dr. Christian Kollmannsberger, Deb Maskens, Ian Hazenberg, Tammy Udall, KCC Executive Director

MARK YOUR CALENDAR

Thursday, March 5, 2009
for the next

Toronto Patient Meeting
and Live Webcast

Attend in person or join us on-line

Contact us to arrange a webcast location for a group in your area.

Check the website for meeting details, webcast instructions and updates.

Other Canadian meeting locations TBA.

PMH Presents www.kidneycancercanada.ca Website Domain to KCC

Kidney Cancer Canada held its first ever planning meeting on October 11, 2006. It was attended by about 15 kidney cancer patients and caregivers. Shortly thereafter the first website

www.kidneycancercanada.org was created. "We had no idea that within a year we would be establishing a national non-profit organization", says Chair of KCC, Tony Clark, "or that our website activity would grow so quickly."

Princess Margaret Hospital in Toronto had previously purchased several website domains related to kidney cancer. On May 22, 2008 Dr. Jennifer Knox and Dr. Michael Jewett presented Kidney Cancer Canada with the ".ca" website domain www.kidneycancercanada.ca. Many thanks to PMH for their generosity.



L to R: Laura Legere, R.N., Dr. M. Jewett, Deb Maskens, Tammy Udall, Tony Clark, Dr. J. Knox and Joan Basiuk, R.N.

Volunteer Spotlight

Ian Hazenberg - Director, British Columbia

April 24, 2004, Ian Hazenberg was diagnosed with having a tumour the size of a grapefruit on his right kidney. Five days later it was removed. Although the tumour was cancerous, the operation was a success and life pretty much got back to normal.

One year later, Ian came down with what he thought was the flu. A series of tests were done and during exploratory surgery, it was discovered that the cancer had metastasized to his lungs. In August Ian was told that there wasn't any proven effective treatment for renal cell carcinoma and that he had about 2 years to live. But in December Ian agreed to be involved in a clinical trial of a drug called SU011248 (Sutent).

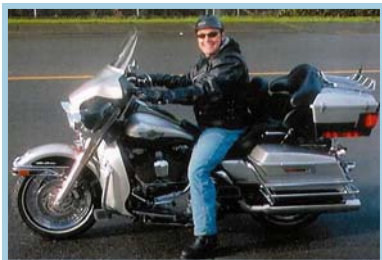
Thirteen months later the tumour had reduced to the size of an acorn and had become completely transparent so Ian stopped taking Sutent. The following August Ian started taking the drug again because the tumours were growing. This time it did not work.

Amazingly, in February 2008, Ian was able to start a new clinical trial with ABT-869; a trial for patients with renal cell carcinoma that no longer respond to

Sutent. After some dosage adjustments Ian is doing much better.

If it wasn't for these clinical trials Ian is convinced he would not be here telling his story today.

In early 2008 Ian accepted an invitation to join the KCC Board as the Director for British Columbia. In his role Ian has



worked to increase the patient membership base in B.C., create awareness about KCC through media interviews and speaking engagements, act as a liaison between KCC and its stakeholders in B.C. and help organize

the first ever B.C. patient information and support meeting.

For Ian, this has been an amazing experience. Ian states that there is a perspective and caring that he has learned entirely because of his cancer and his involvement with Kidney Cancer Canada.



Ian and his family

To receive the **KCC Newsletter**

& other important updates via email visit the website at www.kidneycancercanada.ca

Simply visit the KCC home page and click on

'Join Now'

Volunteers Needed

KCC welcomes patients and caregivers to help spread the word about our organization in every province. We particularly need volunteers in Quebec to help with our French language website and future patient meetings in Montreal and Quebec City.

Please contact: info@kidneycancercanada.ca

2008 KCC Board Members

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Vice-Chair

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