Kidney Cancer Canada

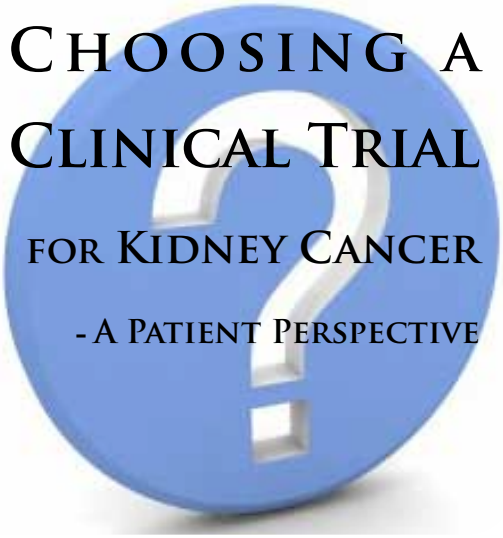
Newsletter

June 2009

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

Choosing a Clinical Trial for Kidney Cancer

- A Patient Perspective



Five years ago there were only a few clinical trials available for renal cell carcinoma in Canada. Today, there are trial options available for all stages of kidney cancer. As a patient, you might have the opportunity to join a trial for the surveillance of small renal masses, the use of targeted therapies before or after surgery, or for the use of promising new therapies for metastatic renal cell carcinoma (mrcc).

Many patients with kidney cancer will at some point have the opportunity to join a clinical trial. The dilemma for many patients is whether to choose an approved treatment or take the chance on a newer drug or combination. In some cases, patients may even be able to choose between clinical trials for their stage of disease.

How to Investigate Clinical Trial Options

Any patient or caregiver can research available clinical trials. One great website for researching trial opportunities is www.clinicaltrials.gov This website includes trials that have trial sites in Canada. To use the website:

1. Start by searching for trials for renal cell carcinoma.
2. Hide studies that are not seeking new volunteers.
3. Review each study's inclusion and exclusion criteria. Some studies exclude patients who have had any prior treatment. Others will limit the study to one other prior treatment or list other specific requirements.
4. If the study looks promising, contact the closest site coordinator and ask for more information. Remember that the studies all need volunteer patients, so you have every right to ask for more information.
5. Take the information about the trial to your primary oncologist for an opinion about the value of the trial for you specifically. Some trials may offer you a great opportunity. Others may be intensive in terms of scanning, clinic visits and possible side effects.

At KCC, we often hear from patients who are considering trials. One thing to remember is that the right trial for you might not be offered at your current cancer centre, even if you are a patient at one of the major cancer centres in your province. You might ask why your centre isn't offering a trial that is being offered somewhere else in your province or elsewhere in Canada. Sometimes the decisions about what trials are run come down to resources – a hospital can only afford to take on so many trials. At other times, your hospital might be offering a competing trial – a different trial for the same population of patients. Depending upon your comfort level, you may want to investigate trials in other cancer centres in your province, the province next door, and in rarer cases, even at centres in the United States. Generally it is very difficult for patients to travel great distances for a clinical trial which almost always involves many repeat visits. Occasionally it may well be worth it. Please remember you can discuss these trial options with your oncologist even if they are not participating in that trial.

One Patient's Perspective

I am currently on my second clinical trial. Choosing the first clinical trial was an easy decision: there were no other available treatment options for my disease way back then. Choosing the second trial presented more of a dilemma. Here's how I thought through my decision:

Factor One: Insurance Coverage

Because I am lucky enough to have private insurance, I think that I may be able to access Health Canada approved drugs (Nexavar, Sutent, Torisel) should

(Continued on page 3)

Is Access to One Treatment Enough?

Fellow patients, caregivers, and friends,

As many of you know, we have all worked hard to ensure that new treatments for kidney cancer are accessible to all patients from coast to coast. We have been delighted to announce broad public coverage of Nexavar and then Sutent. We continue to ask for your help to make Torisel accessible outside of the provinces of Nova Scotia and British Columbia where decision makers have taken a leadership position for kidney cancer patients.

The issue before us now is the need for sequential treatments. For many types of cancer, if one type of treatment stops working after a time, the patient can switch to a second, third or fourth treatment. Through access to sequential lines of treatments, patients with metastatic disease can continue to manage their disease and enjoy a good quality of life for many years to come.

Unfortunately, with kidney cancer, treatments have only been approved as first-line therapies (meaning that they are approved as the first drug you receive). Some patients do very well on one drug for many years. Others may find that the drug is not helping them at some point and then would need to switch to another therapy.

Most oncologists specializing in kidney cancer are seeing increasing evidence that these drugs can be used very effectively one after the other. In some provinces, patients who have private insurance and those who can self-fund their treatments have access to many treatments in sequence, extending their survival for years. Sadly, those patients who depend upon public reimbursement for their treatments have fewer options. If a clinical trial for a second drug is not available, these patients simply have no access to other Health-Canada approved therapies for mrcc.

We encourage all patients and family members to join us in promoting more flexible access to all Health-Canada approved therapies for kidney cancer. As we have said before, your treatment choice should be a choice between you and your oncologist.

We look forward to you joining our campaign.

As we say at KCC…ONWARDS!

Tony Clark
Chair, Kidney Cancer Canada

Kidney Cancer Research Network of Canada

At this year's Canadian Kidney Cancer Forum, medical researchers from across Canada established the Kidney Cancer Research Network of Canada (KCRNC). The vision of this research network is to promote kidney cancer research to make Canada a global leader in the management of kidney cancer.

The initial projects to be undertaken by KCRNC are:

- An initiative looking at the indicators for quality in the care of kidney cancer patients
- Development of guidelines for genetic testing of kidney tumours
- Establishment of a Canadian Kidney Cancer Database
- Implementation of the Canadian Urology Association's Follow-up Guidelines for the care of patients after surgery; and
- Support and improvement of the mechanisms to conduct clinical trials through existing or new Canadian organizations.

KCRNC will collaborate closely with Kidney Cancer Canada (KCC) on these initiatives and their virtual network will be hosted on the KCC website.

Photo (Right) was taken at the 2nd Canadian Kidney Cancer Forum in January 2009.

KCC Patient Meetings

Upcoming Dates:

Kidney Cancer Canada will be hosting meetings in St. John's, NL on June 9th & Halifax, NS on June 10th. Check the website for fall dates in Ottawa, London, Saskatoon and Greater Vancouver.

(L-R) Joan Basiuk, Dr. Michael Milosevic and Deb Maskens

(L-R) Dr. Pierre Karakiewicz, Deb Maskens, Tony Clark and Élise Andreoli, R.N

Kidney Cancer Canada Establishes Medical Advisory Board

Dr. Jennifer Knox

KCC has recently undertaken the important step of establishing a Medical Advisory Board (MAB). At our Annual General Meeting held in January 2009, Dr. Jennifer Knox, an oncologist at Princess Margaret Hospital, was asked to be the first Chair of the MAB. Dr. Knox accepted this position with pleasure. Invitations were then sent to 17 Canadian specialists with an interest in the field of kidney cancer. All 17 specialists immediately accepted our invitation. The outstanding calibre of our MAB is definitely a tribute to the success of KCC and its recognition in the medical community.

Membership on the Medical Advisory Board will reflect the geographic diversity of Canada and will also represent both official languages. As well, members will come from the various medical specialties of urology, medical oncology, radiation oncology and nursing. KCC's Director of Medical Relations, Joan Basiuk, will act as a liaison between KCC and its Medical Advisory Board.

The main responsibilities of this board are to:

- Provide medical counsel for the KCC board's activities
- Provide oversight for the health information given to KCC members on our website
- Suggest topics & speakers for KCC educational meetings held in their region
- Provide a link to the Canadian medical community, and
- Promote public awareness of KCC in their regions, nationally and internationally.

(Clinical Trials - Continued from page 1)

I need them in the future. (Sadly this is NOT true for all patients – so much depends upon your plan provider, your policy, and your province of residence.)

Factor Two: Saving Available Options

Since I plan to live a long time with this disease, my treatment plan will require a series of different drugs, one stepping in where the previous drug leaves off. From researching options, I have learned that patients have the most treatment options in the 1st and 2nd line settings (your first and second drug for treating mrcc). Somehow this feels as if I have two poker chips – and I want to play them strategically to maximize my drug options down the road. So, for me, the best choice for my 2nd line treatment was to access a brand new agent available only through a clinical trial and "save" the Health Canada approved treatments for down the road.

Considerations for Other Patients

For many patients in Canada, a clinical trial may be the only way to access drug therapy. This is especially true for patients needing second-line treatment or those with non-clear cell rcc. This is an important consideration. Most drugs are available through research programs much earlier than otherwise available.

For patients without private insurance, another consideration that should be discussed is whether taking a trial drug will prevent you from accessing another proven drug in the future. For example, if you participated in a first-line trial of pazopanib vs. Sutent and were assigned pazopanib, would you be able to access another drug (e.g., Sutent) in the second line? Unfortunately reimbursement agencies in Canada have been quite rigid about what is allowed in the first line, and few are reimbursing anything in the second line (except for Nexavar following a cytokine such as Interferon).

An important consideration is whether you will benefit from participation in a clinical trial. The short answer is that we simply do not know – hence the reason to conduct the clinical trial and find that answer. If you choose to participate, you know that you will be monitored very closely for the duration of the trial.

Whatever you decide, taking a proactive role in your treatment plan is the best approach. Through KCC, you can connect with other patients and caregivers who have already researched information about rcc trials. Often informed patients and caregivers have the insider track on what's available – and where.

Thanks to all of you who have participated in a previous trial in some way – we wouldn't have the treatments we have today without you.

For more information about clinical trials, go to: www.kidneycancercanada.ca/resources and click on 'Clinical Trials'.

Written by Deb Maskens

Deb is the Vice Chair of Kidney Cancer Canada and has been a kidney cancer survivior for over 30 years.

Kidney Cancer Canada

A Great Place for Early & Advanced Stage Patients

Jolene's Story

By Jolene Willacy

Patients are diagnosed with kidney cancer in many different ways; some are in an emergency room after an acute episode and others find out 'incidentally' while looking for something else. This was my situation.

Four years ago I learned I had kidney cancer while I was at my family doctor's office receiving routine test results. I was a non-smoker who looked and felt healthy so this news was quite a shock to hear.

After being referred to a urologist, I was informed that I had a 4.8 cm tumour on my left kidney pushing into the adrenal gland. There was a small mass on my right ovary and another on my left lung.

I had a radical nephrectomy to remove the kidney and adrenal gland. After the surgery I learned that the cyst on the ovary was benign and that the tiny mass on my lung was just scar tissue. Despite this, I continued to worry about what my future might hold.

Once surgery is done, early stage patients like me are often sent back to their family physicians for follow up care. Patients are frequently told 'We got it all' with no recommendations for follow up. Yet in my experiences meeting other Stage I and II patients, I have seen several instances of metastatic disease appearing years or even decades after surgery.

New follow up guidelines for care are available at the Canadian Urological Association's website. I would recommend that all patients take these guidelines to their physician to discuss them. For me, having these guidelines has allowed me to be more diligent with my follow up care.

During my early diagnosis and recovery I was also frustrated to find that there was very little information or support available for Canadian patients. I felt very anxious and alone during this time. Fortunately I was able to connect with some other Canadian patients who shared my frustrations. Not long after making this connection, Kidney Cancer Canada (KCC) was formed by this same group of patients.

I encourage all patients (including early stage patients) to become members of Kidney Cancer Canada. There is a wealth of information and support available including a discussion forum and regular patient meetings throughout Canada.

I volunteer for KCC as their treasurer because of the positive impact they have had on my life and the lives of other patients.

Today I continue to cope well not only by volunteering for KCC, but also through keeping a journal, enjoying music, exercising, meditating, being proactive in my care and maintaining a positive outlook.

To download the 'Follow-up guidelines after radical or partial nephrectomy for localized and locally advanced renal cell carcinoma' go to: www.cua.org/guidelines/rcc_e.pdf

To join Kidney Cancer Canada go to www.kidneycancercanada.ca

KCC Volunteer Opportunities

Cancer Clinic Liaison

Individuals are required in every province for this volunteer role. The Liaison is responsible for distributing KCC communications materials at local cancer clinics, urology centres and other relevant locations. The goal of this role is to increase awareness and reach more patients and families who are diagnosed with kidney cancer.

For other volunteer opportunities, please contact Tammy Udall, Executive Director at:

1-866-598-7166

tammyudall@kidneycancercanada.ca

New Live Chat

Kidney Cancer Canada is offering live chats for patients and caregivers. We invite you to join one of KCC's scheduled chats. Check the website for dates and times. You may also arrange your own time to chat with another KCC member or group of members.
Note: You need to be a KCC member to participate. Sign up for a membership at www.kidneycancercanada.ca

We welcome your feedback and suggestions for future chat topics. Please send your comments to info@kidneycancercanada.ca

This publication is made possible by the contributions of numerous volunteers. If you have questions or ideas for future newsletters please contact Kidney Cancer Canada at

info@kidneycancercanada.ca

1-866-598-7166