



Kidney
Cancer
Canada

FALL 2011



NEWSLETTER

New Directions in Clinical Trials for Kidney Cancer

By Dr. Nina Baluja, KCC Director for Ontario

Clinical trials offer eligible patients the opportunity to play an active role in their own healthcare and gain access to new research treatments before they are widely available. Patients are also able to obtain expert medical care at leading healthcare facilities during the trial and help others by contributing to vital research in kidney cancer.

Beginning in 2005, exciting times started in kidney cancer research with positive clinical trial data with Sutent & Nexavar, leading to their subsequent Health Canada approval. Since then, a number of agents have proven promising and have led to other Health Canada approvals, including Afinitor, Torisel and Votrient.

What New Agents are Available in Clinical Trials?

In addition to existing agents being tested in new settings, the following new agents are currently in trials in Canada:

A new agent **tivozanib** (AV-951) is currently being tested in the first line setting versus sorafenib (Nexavar). Tivozanib is an oral, anti-VEGF agent.

Abnormal Notch signaling is implicated in many human cancers, including kidney cancer. **RO4929097** is an inhibitor of gamma-secretase, a key enzyme in Notch activation. This new agent is currently being investigated for second-line treatment of kidney cancer in patients who have progressed on prior anti-VEGF therapy.

Programmed death-1 (PD-1), is a molecule that slows down the body's immune responses. **BMS-936558** is an antibody

that blocks PD-1. A clinical trial is underway investigating this molecule in clear cell kidney cancer, in patients who have progressed on anti-VEGF therapy.

Dovitinib (TKI258) is a new oral inhibitor of VEGFR (vascular endothelial growth factor receptor) and FGFRs (fibroblast growth factor receptor). A third-line trial is ongoing to evaluate dovitinib versus sorafenib (Nexavar) in patients who have progressed on two lines of therapy including an anti-VEGF and mTOR inhibitor.

What Research Questions Are Important for Kidney Cancer?

For other types of cancer, known biomarkers (such as HER2 for breast cancer) allow oncologists to target the best treatment for the specific type of tumour. Biomarkers are essential pieces of the puzzle that help oncologists select the right treatment for the right patient. Kidney cancer researchers are now focused on identifying biomarkers for kidney cancer.

Most tumours target certain cell division and multiplication pathways, leading to uncontrolled cell division and tumour growth. Our understanding as to how tumours overcome these pathways and grow remains very limited. Biomarker analysis might help us understand this better. If we know what triggers tumours, we might be able to control them. Biomarker analysis remains a very important element in kidney cancer trials. It is very important that patients participating in trials agree to Biomarker analysis, which often involves genetic testing.

Currently, in Canada there is one specific Biomarker trial ongoing, which evaluates biomarkers in blood and archived tissue samples, and their correlation with clinical activity and/or treatment-related toxicity in subjects with advanced kidney cancer.



Dr. Nina Baluja

How Do I Find Out More About Clinical Trials?

Many cancer centres across Canada offer clinical trials for kidney cancer. Currently there are at least 39 clinical trials ongoing in Canada for kidney cancer. [KCC lists these trials on our website](#). For ease of use, we have categorized these trials as Neo-Adjuvant (pre-surgery), Adjuvant (immediately post-surgery), First-Line, Second-Line, Third Line, Surgery and Biomarker trials. KCC updates the list, including all known trial sites in Canada, on a regular basis.

Andre's Story

By Maria Leblanc

My husband Andre was the owner and operator of a local building supply store in Cap-Pele, New Brunswick when he was diagnosed with kidney cancer. He was 50 years old, and we had been married for 18 years. At that time Andre had just sold his business.

Having passed blood in his urine a couple of times throughout the year, his family physician sent him for an ultrasound and found a large tumour on his right kidney in October of 2005. It was removed in January, 2006 and we were told everything went well and all surrounding lymph nodes were clear.

Six months later, enlarged lymph nodes in the chest area were seen in the scan. These were determined to have been there before the surgery and had been overlooked; so they would be observed. Andre didn't have any pain whatsoever and was feeling in good health. The observation continued for the next four years. Then the lymph nodes enlarged further. We knew, after consulting with the kidney cancer specialist, and the Kidney Cancer Canada website, that our best option was sunitinib (Sutent), but our local oncologist recommended Interferon because of the high cost of Sutent.

We had no health insurance. The stress of dealing with the progression of the disease, added to the cost of treatment was certainly overwhelming at times. The money we had put aside for retirement would be needed to fight this disease. Fortunately, another local hospital had a study comparing pazopanib with sunitinib. I guess we could say that the decision to start treatment was as much financial as a medical one. In May of 2009, Andre was put on Sutent and is presently on his 20th cycle. Of course there are side effects; but the treatment has worked very well and has kept the disease stable for the past two years.

Unfortunately, we know that Sutent will eventually stop working; maybe next week, next month or next year – only time will tell. Then, Andre will need to have access to the best second-line treatment available. Everolimus (Afinitor) was approved by Health Canada as a second-line treatment in January 2010. We are thrilled that New Brunswick has decided to get on board with the other provinces and approve this treatment in July 2011; giving NB patients the best care possible.

The kidney cancer website has been very informative with treatment options, side effects and recent news. It has been a blessing for us. I visit the website at least once a week; reviewing the latest information.



Andre, along with a few friends, has just started a local support group for people with all types of cancer. More and more people keep showing up for the meetings. This shows how important it is to have a place to meet and speak with people who are going through the same emotions. This will certainly continue as an ongoing project. We both think that a positive attitude is a great tool to fight all kinds of diseases.

Apart from a little fatigue, Andre is in fairly good health and living his day-to-day life.

Research Fellowship

By Deb Maskens, Chair of KCC

Kidney Cancer Canada (KCC) believes so passionately in the need for more kidney cancer research that in 2010, we made the commitment to fund a research fellowship. We are pleased to announce that our first research fellowship, named in honour of Tony Clark, a co-founder of KCC, was awarded this spring to Dr. Severa Bunda at the University of Toronto. Dr. Bunda obtained her PhD in cardiovascular research but after a family member developed metastases from colon cancer, her research focus shifted to the issues of the development of metastases.

The von Hippel-Lindau (VHL) gene has been known for years to play an important role in the development of kidney cancer. Recently, the research team at the University of Toronto discovered a link between the von Hippel-Lindau (VHL) gene and the Janus kinase 2 (JAK2) gene. JAK2 is involved in the proliferation, activation, migration and death of cells. Dr. Bunda's research will look at the mechanism by which VHL regulates JAK2 in kidney cancer. Her hope is that "the lessons learned from my research will provide better understanding of kidney cancer development and progression, and ultimately aid in the development of novel cancer therapies".

Dr. Bunda will be working under the supervision of Dr. Michael Ohh, a well known and respected scientist in the field of kidney cancer research. Dr.



Dr. Bunda and Dr. Ohh at the lab

Ohh is a Professor in the Department of Laboratory Medicine and Pathobiology and currently holds the Canada Research Chair in Molecular Oncology. He has spent much of his career investigating the von Hippel-Lindau (VHL) gene and its role in cancer, especially kidney cancer.

Kidney Cancer Canada will fund Dr. Bunda's research fellowship through our Onward Research Fund in partnership with the Canadian Institutes of Health Research's Small Health Organization Partnership Program.

Thank you and Farewell



In April 2008, I was given the incredible opportunity to serve as Kidney Cancer Canada's first Executive Director. When I became part of the KCC team, it was in a part-time capacity and the organization operated on a shoestring budget under the leadership of a few very dedicated volunteers. It was a young and quickly evolving non-profit patient group. During my three year career with KCC, I helped support the organization through vast growth and change and at the same time saw my role grow and evolve.

On July 8, 2009, KCC became a nationally registered health charity; allowing people to donate to help support and educate the 5000 plus Canadians who are diagnosed with kidney cancer each year. In early 2010, the board of Kidney Cancer Canada made a commitment to work towards addressing a recognized serious gap in the funding of kidney cancer research. Later that year, the Onward Research Fund for Kidney Cancer was created in honour of co-founder Tony Clark; a man who has proven to be one of my greatest role models. A partnership was established with the Canadian Institutes for Health Research (CIHR) allowing every dollar raised by KCC for research to be matched by the CIHR.

I have witnessed so many other significant accomplishments over these past three years including the approval of funding for several new treatment options for kidney cancer, the establishment of a highly-regarded Medical Advisory Board and the execution of two National Patient Conferences. My greatest reward has been seeing the incredible difference this organization has made in the lives of patients with kidney cancer.

In September I will be leaving KCC to allow me to focus more time on my family. I will greatly miss this organization and all of the patients, family members, dedicated volunteers and board members from right across Canada that I have had the distinct privilege of meeting and working with. I am incredibly proud to have been a big part of assisting KCC during this time of growth and change.

As they say at KCC, ONWARD!

Tammy Udall

Upcoming Events – Fall 2011

- ▶▶▶ Wed., Sept. 28, 2011: 7:00 - 9:00 p.m. (EDT)
Kidney Cancer Survivorship: Looking Toward Your Future*
Featuring Dr. Christina Canil & Dr. Ilias Cagiannos
The Ottawa Hospital Regional Cancer Centre,
Conference Room A & B, 503 Smyth Rd., Ottawa, ON
* Will be available by live webcast
- ▶▶▶ Mon., Oct. 17th, 2011; 7:00 - 9:00 p.m. (PDT)
Ask the Expert
This will be a Q&A session for kidney cancer patients and family members.
Vancouver Cancer Centre, John Jambor Room
610 West 10th Ave., Vancouver, BC
- ▶▶▶ Thur., Nov. 3, 2011: 7:00 - 9:00 p.m. (EDT)
Kidney Cancer in the 21st Century*
Featuring Dr. Stephen Pautler and Dr. Mary MacKenzie,
London Regional Cancer Centre, 3rd Floor, Room 924 AB
790 Commissioners Rd. E., London, ON
* Will be available by live webcast
- ▶▶▶ Tue., Dec. 6, 2011: 7:00 - 9:30 p.m. (EST)
Kidney Cancer: Five Years of Remarkable Progress
Join us for this special event celebrating the five year anniversary of Kidney Cancer Canada.
Featuring Dr. Michael Jewett and Dr. Jennifer Knox
Princess Margaret Hospital, 6th Floor, Auditorium
610 University Ave., Toronto, ON
How to register:
1) Online at www.kidneycancercanada.ca
Click on 'Register for Upcoming Meetings'
2) Call 1-866-598-7166

Kidney Cancer Canada
has adopted the:



**Kidney
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NEWSLETTER

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

Welcome



Welcome to Catherine Madden, the new Executive Director (ED) for Kidney Cancer Canada. Catherine is an experienced Executive Director with a wealth of knowledge in the not-for-profit arena. Most recently, Catherine was the Executive Director with Lupus Canada. We look forward to working under Catherine's leadership as our organization continues to develop and grow.