



**Kidney  
Cancer  
Canada**

# NEWSLETTER

FALL 2012

## Increasing Funding to Kidney Cancer Research

*By Deb Maskens, Chair*

You've heard us say that kidney cancer research is woefully under-funded. From the latest Canadian figures available (2009, published June 2012)<sup>1</sup>, we know that \$545 million was invested in all forms of cancer research in Canada. However, kidney cancer specific research amounted to \$3.64 million (representing just 0.7% of the total investment, and only 1.4% of the funds that are targeted to specific disease sites).

Is that enough? Clearly not, when you consider that kidney cancer is one of the few cancers whose incidence is on the rise across Canada (Canadian Cancer Society Report 2012).

In 2011, a separate report from the Canadian Cancer Research Alliance (CCRA) on Cancer Survivorship Research highlighted that kidney cancer was one of only three cancers to receive \$0 in cancer research investment for survivorship. (Those three cancers were melanoma, pancreatic, and kidney).

### **How does the % of research match incidence rates of kidney cancer?**

In truth, it doesn't. If kidney cancer research was funded according to our incidence rates across Canada, we should be seeing investment at 2.9% (more than double what it is now).

Current Funding: \$3.64 million

Funding if by cancer incidence rate: \$15.8 million

### **Why the funding discrepancy?**

For many years, kidney cancer was one of the less attractive areas of research with few significant breakthroughs. However, in the past 6 years, kidney cancer researchers have developed significant momentum with practice-changing discoveries in many areas from molecular genetics to drug treatments. There are new, important questions with wide ranging implications for kidney cancer and most other cancers that need to be answered. Like

other cancer groups who have achieved greater funding levels, we need to raise awareness of this disease and help to develop new sources of funding for kidney cancer research.

### **Where does cancer research money come from?**

The largest funder of cancer research is the federal government, through the Canadian Institute for Health Research (CIHR) and the Canada Foundation for Innovation (CFI). Charitable groups such as the Canadian Cancer Society and the Terry Fox Foundation are also major funders, as are provincial bodies such as the Ontario Institute for Cancer Research. And then there's the "Voluntary Sector".

### **Role of the Voluntary Sector for Specific Cancer Types**

For kidney cancer in 2009, only 1.2% of all site-specific research funding came from the voluntary sector (charitable vs. government).

#### **Voluntary Sector Contributions by Cancer Site**

	% of Research Funds
Breast Cancer	27.5%
Prostate Cancer	9.1%
Leukemia	6.7%
Kidney Cancer	1.2%

### **How Can We Make a Difference?**

Kidney Cancer Canada is working to make a difference and close the gap in kidney cancer research, but we cannot do it without your help.

Through your charitable donations, we have already funded two CIHR/KCC Research Fellowships specific to kidney cancer, and we have made a sizeable commitment to help fund the Kidney Cancer Research Network of Canada. We have obtained matching funding for our Research Fellowships and look for every opportunity to increase research in kidney cancer.

### **How Can You Help?**

The Kidney Cancer Canada community is a small but amazing group of people who have been touched by this disease – either themselves or through a loved one, a family member, or a friend. We need all of you to help grow our organization's reach and raise funds for patient programs and much-needed research.

Whether you can make us your charity of choice through personal and family donations, run a marathon or do a 5K walk (even if all downhill), we need you to put your thinking caps on help us raise awareness and raise funds.

<sup>1</sup>Cancer Research Investment in Canada, 2005-2009. June 2012. [www.ccra-acrc.ca](http://www.ccra-acrc.ca)



## Research Fellowships

*By Catherine Madden, Executive Director, Kidney Cancer Canada*

In 2010, Kidney Cancer Canada made an important decision to commit to funding their first research fellowship, awarded to Dr. Severa Bunda at the University of Toronto over three years.

Kidney Cancer Canada is pleased to have made the decision this spring to add a second fellowship award to support the research of Dr. Craig Gedye at The University Health Network (UHN). Dr. Gedye is a medical oncologist doing a postdoctoral fellowship under the supervision of Dr. Laurie Elizabeth Ailles.

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# My story

By Noel Denault

At the beginning of September 2002 when I was 60 years old, I was working at Concordia University 4 days a week and spending the other three days doing some major renovations on our home. I was in good physical shape although, for a month or so, I had occasionally experienced some discomfort on my right side and I was feeling more and more tired, which, at the time, I attributed to overwork.

One morning I discovered blood in my urine. I immediately called my family doctor who, thinking that I had kidney stones, arranged for an appointment at the Royal Victoria Hospital. After several medical tests (MRI, scans, x-rays), I got the diagnosis: cancer in the right kidney with a large tumor as well as several metastases in the right lung. The diagnosis hit me like a ton of bricks. What's more, the doctor had no treatment to offer and told me that I had a maximum of 12 months to live.

In early October 2002, I underwent a radical nephrectomy of the right kidney at the Royal Victoria Hospital and four days later, I went home. A series of examinations followed, and surprise: fluid had accumulated between the right lung and the pleura. The treatment involved drawing off the liquid and sealing the area in order to prevent the same thing from happening again. And while the chances of success were small, the surgeon at the Montreal Chest Institute was able to "glue" the membrane to the lung and draw off 2 litres of fluid.

I wanted the best treatment for removing the metastases. I refused the proposed interferon treatment, choosing instead the Interleukin 2 treatment, for which I had to pass a series of physical tests.

What is Interleukin 2? It's an intravenous treatment that acts on the immune system. In my case the treatment was done in three cycles. Each of the cycles involved a week in the hospital (15 injections), a week of home rest, a second week in the hospital (15 injections) and 10 weeks of home rest, before beginning the next cycle. I received a total of 72 injections, which is considered to be a complete treatment.

Very few people qualify for this shock treatment; it is considered to be a fairly dangerous procedure and comes with many side effects which can in turn, cause either the temporary or permanent cessation of treatment.

With enthusiasm, determination, and feeling in good physical shape, I began my treatments in March 2003 at the Montreal Jewish General Hospital with Dr. Patenaude; the treatments continued until November of 2003. I had made my peace with my decision, and the many possible side effects such as loss of appetite, dizziness, hallucinations, fatigue and lack of energy, etc. Then, two weeks into the treatment, tachycardia put me in intensive care for two days where my heart was stopped seven times by the cardiologist. Over the next weeks, I was exposed to *Clostridium difficile* (*C. difficile*), which caused me several problems. But the treatments



continued to the end and after each cycle, the tests showed that the metastases were shrinking rapidly. That was my reward! Now it was a question of time.

At every stage of the illness my wife, my wonderful care-giver, was always by my side. And I had the strong support of colleagues at work and many others who helped me come through what was a difficult time.

My story has a happy ending because after lots of rest and a return to good physical shape, we completed the renovations on our home. That was 10 years ago and regular tests show that the cancer has not returned. Plus, I'm medication-free, except for vitamin D, which I take, on my doctor's recommendation.

## What's New in Treatments for Kidney Cancer?

Together, you and your treatment team will discuss your kidney cancer treatment options. The best approach for you may depend on a number of factors, including your general health, the kind of kidney cancer you have, whether the cancer has spread and your preferences for treatment.

Recent updates in treatment access include:

### **Inlyta**

One of the newest drugs to be approved by Health Canada is axitinib (Inlyta), approved in July 2012. Axitinib is indicated for the treatment of kidney cancer in patients with metastatic renal cell carcinoma (mRCC) of clear cell histology after failure of prior systemic therapy with either a cytokine or the VEGFR-TKI, sunitinib (Sutent). Axitinib is currently being reviewed by pCODR (pan-Canadian Oncology Drug Review) and l'INESSS (Quebec).

### **Votrient**

While not new to Canada, Votrient (pazopanib) has been reviewed by pCODR and is now funded (with conditions) by public drug plans in every province except for Ontario, Manitoba, and PEI.

In the pipeline:

### **Tivozanib**

One keenly awaited drug in 2013 is Tivozanib, being developed by Astellas and AVEO Pharmaceuticals. This drug has been filed for FDA approval in the U.S. for the treatment of patients with advanced renal cell carcinoma.

### **Nivolumab**

A new form of targeted immunotherapy (BMS936558, now known as Nivolumab) will be available through clinical trials across Canada. Please consult our website for updated trials information

### **Dovitinib**

Clinical trials with dovitinib as a third-line agent have now closed to accrual. We look forward to results of the first third-line treatment for kidney cancer in 2013.

## Research Fellowships

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In collaboration with Dr. Michael Jewett and the Uro-Oncology team at Princess Margaret Hospital, Dr. Gedye is working on a project in kidney cancer entitled "Plasticity and Sensitivity of Renal Cell Carcinoma Cancer Stem Cells". Dr. Gedye simplifies his research with the statement that, "One reason why treatments for kidney cancer might fail is that cancers may be like beehives, with rare "queen-bee" cancer cells and more common "worker and drone" cancer stem cells. These "queen-bee" cancer cells or so-called "cancer stem cells" may be the specific cells that spread to form metastases and resist treatment." Dr. Gedye stated that "the support of Kidney Cancer Canada's CIHR Postdoctoral Fellowship will allow me to continue my research which will hopefully have significant impacts for the understanding and treatment of kidney cancer."

Kidney Cancer Canada is pleased to fund the research fellowships of both Dr. Bunda and Dr. Gedye through our Onward Research Fund, named in honour of our co-founder Tony Clark, and in partnership with the Canadian Institutes of Health Research's Small Health Organization Partnership Program.

# Birth of the Kidney Cancer Research Network of Canada



*Left to right – Paul Shay, Kidney Foundation of Canada; Dr. M. Gospodarowicz; Dr. Michael Jewett; Dr. Colin Carrie, Parliamentary Secretary to the Minister of Health; Deb Maskens, Chair, Kidney Cancer Canada; Catherine Madden, Executive Director, Kidney Cancer Canada*

**By Joan Basiuk**

Recent years have brought tremendous improvements in the treatment of kidney cancer. However, significantly more research is required to improve the outcomes for all patients with this disease.

At the 1st Canadian Kidney Cancer Forum held in Mont Tremblant in 2008, the formation of a research network was proposed to address this unmet need. Now, four years later, the Kidney Cancer Research Network of Canada (KCRNC) is officially born.

On June 15th 2012, the Canadian Institutes of Health Research (CIHR) announced that it has partnered with the Kidney Foundation of Canada and Kidney Cancer Canada to provide \$600,000 over three years to support the KCRNC.

The network is led by Dr. Michael Jewett, a uro-oncologist at the University of Toronto/Princess Margaret Cancer Centre. The network brings together kidney cancer survivors, expert clinicians, and researchers from across Canada to facilitate national collaboration on research strategies, clinical trials, and resources for the treatment of patients. Membership in the network is inclusive and on the request of any applicant who has demonstrated interest or expertise in kidney cancer or related areas. The KCRNC will work in close collaboration with Kidney Cancer Canada in the coming years.

Specific goals of the KCRNC include:

- Establishment of a Canadian patient information system linked to a tissue bank
- Support of existing groups to encourage the development of clinical trials on potential new treatments
- Development of quality indicators to measure the quality of care and optimize outcomes for kidney cancer patients
- Development of standards for genetic testing and counselling
- Creation of a survivorship care plan with a detailed strategy to make it available to all patients with kidney cancer
- Research on the sub-types of kidney cancer to help develop personalized medicine strategies.

Under the umbrella of the KCRNC, research teams comprised of expert clinicians, researchers and survivors will tackle four major initiatives:

- 1) Genetics Awareness and Practices
- 2) Personalized Medicine for Kidney Cancer
- 3) Quality of Kidney Cancer Care
- 4) Survivorship.

Ultimately, the network hopes to bring awareness to kidney cancer as a significant health issue and to address the need for increased focus on kidney cancer research across Canada.

## Don Kurylo Memorial Golf Tournament

*Submitted by :Tournament Committee*

The 2nd Annual Don Kurylo Memorial Golf Tournament took place Saturday, June 23, 2012 at the Sault Ste Marie Country Club.

As Don was one of the founding members of Kidney Cancer Canada while battling the disease himself, all proceeds from the tournament will be donated directly to KCC.

As Don was a long-time hockey volunteer, coach and Ontario Hockey League scout, the tournament consisted of family, friends, past hockey affiliates, colleagues and prominent community members. The outpouring of support from the community was remarkable in terms of sponsorships, prizes and monetary donations. In only its second year, the tournament was a sell-out, and surpassed last year's fundraising total of \$9 000.

The organizing committee was honoured to host Catherine Madden, Executive Director of Kidney Cancer Canada, on the day of the tournament. Her presence added validity to the tournament as she shared information regarding the importance of KCC and the progress made in its short period of existence. She also relayed regards from Deb Maskens, a friend and member of Don's original patient group, who mentioned some details about Don's involvement, really hitting home and pulling on the heart strings of those in attendance.

The organizing committee is extremely pleased to donate a cheque for \$13,500 to KCC. We cannot thank EVERYONE enough for their support and generosity in making this tournament a success. I know Don would be honored and proud of the caliber of the tournament. He loved nothing more than friends gathered in laughter, friendly competition and camaraderie. Thank you for being a part of his legacy and we look forward to next year. FORE!!!



## Kidney Cancer Canada Award of Excellence in Kidney Cancer Nursing

Kidney Cancer Canada Director of Medical Relations Joan Basiuk presented Paul Vincent O'Brien, RN CON (c), BA with the Kidney Cancer Canada Award of Excellence in Kidney Cancer Nursing at the 2012 CANO Conference this fall.



This CANO (Canadian Association of Nurses in Oncology) award is sponsored by Kidney Cancer Canada in honor of our co-founder, Tony Clark, and acknowledges an oncology nurse who has made an exceptional difference in the lives of kidney cancer patients.

Paul currently practices as a primary nurse in the outpatient department of the London Regional Cancer Program. Paul's clinical focus has been in oncology since 1988 with multiple years of experience in the inpatient, outpatient and the community care of cancer patients. Paul's past experience also includes time as a Research Coordinator with the Lawson Translational Cancer Research Cancer Team in London Ontario. The focus of the team was on the collaboration between multiple disciplines to facilitate the translation of basic scientific discoveries at the bench into clinical practices at the bedside. Paul's professional interests are focused on collaborative practice, nursing research and patient empowerment.

Congratulations Paul!

## Upcoming Patient & Caregiver Meetings

- ▶▶▶ **VANCOUVER** – Monday, Oct 22nd, 2012  
**Current Treatments for Kidney Cancer – VANCOUVER**  
TIME: 7:00 to 9:00pm *Meet and greet, with refreshments, begins at 6:30pm*  
WHERE: Vancouver Cancer Centre, John Jambor Room  
600 West 10th Ave. Vancouver, BC  
FEATURING: **Dr. Peter Black, Uro-oncologist-UBC**  
**Stephen Andrew, CTV Broadcaster**  
(Pre-registration required)  
*This meeting will also be offered by live webcast*
- ▶▶▶ **CALGARY** – Wednesday, Oct 24th, 2012  
**Gain New Insight into Kidney Cancer – CALGARY**  
TIME: 7:00 to 9:30pm *Meet and greet, with refreshments, begins at 6:30pm*  
WHERE: Tom Baker Cancer Centre, Auditorium, Main Floor  
1331 29th St. NW, Calgary, AB  
FEATURING: **Dr. Daniel Heng, MD, MPH, FRCPC**  
**Dr. Jun Kawakami, MD, FRCPC, DABU**  
**John Robinson, PhD, Clinical Psychologist**  
**Glenda Mee, RN, BN**  
(Pre-registration required)  
*This meeting will be broadcasted live to Edmonton, AB*
- ▶▶▶ **EDMONTON** – Wednesday, Oct 24th, 2012  
**Gain New Insight into Kidney Cancer – EDMONTON (Videoconference)**  
TIME: 7:00 to 9:30pm *Meet and greet, with refreshments, begins at 6:30pm*  
This meeting will be held in Calgary with a videoconference to Edmonton, AB  
WHERE: Cross Cancer Institute, Zane Feldman Auditorium  
11560 University Ave., Edmonton, AB  
\*This meeting will be held in Calgary with a videoconference to patients, caregivers and healthcare professionals gathered together in Edmonton, AB  
\*\*Kidney Cancer Canada Director for Alberta David Chatters and Catherine Madden, Executive Director will be on site in Edmonton to welcome attendees, provide information and assistance.  
(Pre-registration required)
- ▶▶▶ **HAMILTON** – Tuesday, Nov 6th, 2012  
**How We Can Treat & You Can Cope with Kidney Cancer Better – HAMILTON**  
TIME: 7:00 to 9:00pm *Meet and greet, with refreshments, begins at 6:30pm*  
WHERE: Juravinski Cancer Centre, Lecture Theatre  
699 Concession St., Hamilton, ON  
FEATURING: **Dr. Anil Kapoor, BSc, DEng, MD, FRCS(C) Surgical Oncologist**  
**Linda Learn, MSW, RSW, Social Worker**  
(Pre-registration required)  
*Also available as a live webcast*
- ▶▶▶ **HALIFAX** – Thursday, Dec 6th, 2012  
**Kidney Cancer Canada Support Meeting – HALIFAX**  
TIME: 6:00 to 10:00pm *Meet and greet, with refreshments, begins at 5:30pm*  
WHERE: QEII Sciences Centre, Dickson Building, Room 5110  
FEATURING: **Dr. Ricardo Rendon**  
(Pre-registration required)  
*Also available as a live webcast*
- ▶▶▶ **VANCOUVER** – Saturday, March 9, 2013 **SAVE THE DATE**  
**A Path to Living Well**  
**Kidney Cancer Canada 4th Annual Patient Education Conference – VANCOUVER**  
TIME: 9am to 4pm (PST)  
WHERE: Delta Vancouver Airport  
3500 Cessna Drive, Richmond, BC  
(Pre-registration required)

Check our website for additional information at [www.kidneycancer.ca](http://www.kidneycancer.ca) under "Events"

How to register:

- 1) Online at [www.kidneycancer.ca](http://www.kidneycancer.ca) click on "Events" then "Upcoming Meetings"
- 2) Call 1-866-598-7166

## Patient & Caregiver Meet & Greets

### Montreal, Quebec

Kidney Cancer Canada held a patient meeting on September 12 at a small Portuguese restaurant in Montreal. We were very pleased to meet the ten patients and caregivers who responded to our invitation and who generously shared their stories about kidney cancer. One of those stories, Noël Denault's experience with interleukin 2, is featured in this Bulletin (merci Noël!). We were also graced with the presence of Nathalie Bedu who is a founding member of the patient arm of A.R.Tu.R, the kidney cancer association of France. A fellow MRCC patient, Nathalie talked to us about her experience with kidney cancer as well as her volunteer work with other "Arturians". We plan to organize an "encore" in the Spring of 2013, when we are hopeful that those of you who couldn't make it this time, will be able to attend.

### Winnipeg, Manitoba

On Tuesday May 8, 2012 an engaging group of 30 kidney cancer patients and caregivers joined our Executive Director Catherine Madden and me at the Round Table Steak House for our first Manitoba "Meet & Greet" event. We were very pleased to also have Dr. Darrel Drachenburg, Dr. Joel Gingerich and Dr. Tom McGregor join us for dinner and share in this opportunity for patients and caregivers in the province of Manitoba to come together and share their stories of hope and inspiration. We have since followed up with several attendees who are interested in working together to provide peer support to others as well as assist in helping to broaden awareness of kidney cancer and the services provided by Kidney Cancer Canada in the province. Thanks to all who attended and shared their stories!

### Halifax, Nova Scotia

Kidney Cancer Canada's coordinator Maryse Tremblay and Director for Quebec Nicole Giroux, hosted the Halifax patient and caregiver meeting this past June 7. There was a great group of people in attendance who came from different parts of the Maritimes.

Speaking at our meeting was Dr. Lori Wood medical oncologist at the Queen Elizabeth II Hospital in Halifax, as well as Associate Professor at the Department of Medicine and Urology of Dalhousie University. As a specialist in genitourinary malignancies, Dr Wood also does much needed research in kidney cancer. Dr. Wood provided the audience with a comprehensive and inspiring lecture on kidney cancer – all stages included – as well as an up-to-date and fascinating perspective on new treatments coming down the pipeline!

MRCC patient, Chris Patriquin, shared his very personal and deeply moving experience with stage IV kidney cancer. An example of courage and resilience, Chris and his wife Vickie pitched in to help with the registration and set-up.

The meeting was concluded with two break-out sessions where patients and caregivers exchanged stories, tips and encouragement. Great thanks to Dr Lori Wood and Registered Nurse Heather Walker, who graciously hosted the patient's session. Heather is the current Team Lead for the clinical staff of ACCRU – The Atlantic Clinical Cancer Research Unit.



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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@kidneycancer.ca](mailto:info@kidneycancer.ca) • 1-866-598-7166

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