



Kidney
Cancer
Canada



NEWSLETTER

WINTER 2010

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

Cancer Research Funding:

Does Kidney Cancer get its Fair Share?

In 2007, \$402.4 million was invested in cancer research in Canada. Of that total, 1.14% was invested specifically in research for kidney cancer. Is that enough?

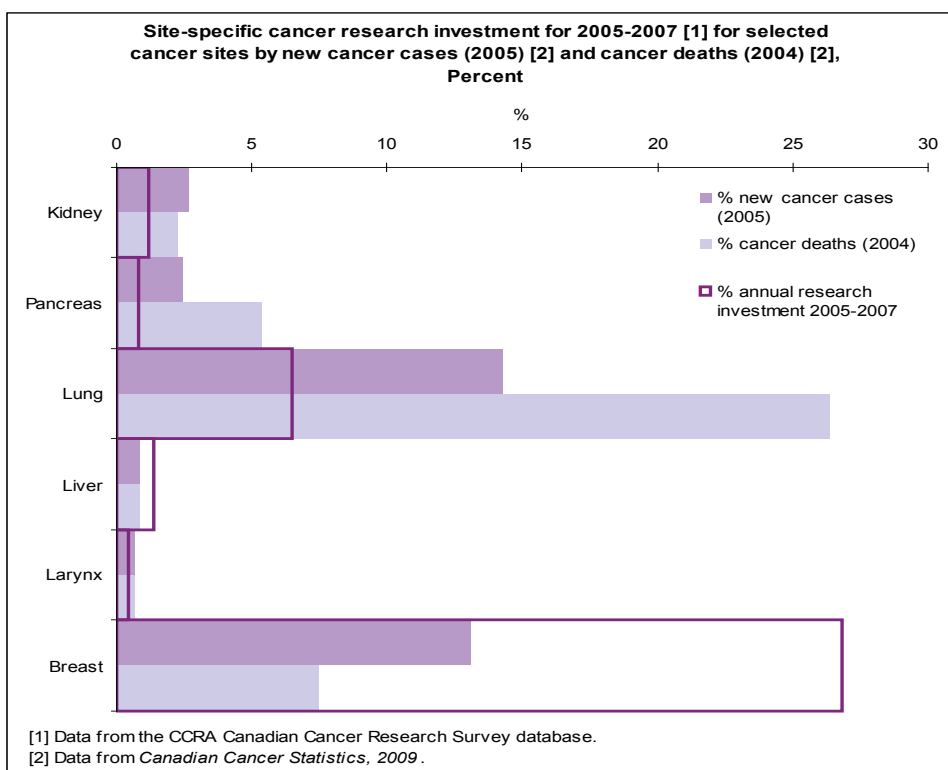
Investment in kidney cancer research has been consistent over the past three reported years:

2005:	1.19%
2006:	1.17%
2007:	1.14%

The annual report, Cancer Research Investment in Canada, 2007, shows that over the past three years, more than \$1.1 billion has been invested in cancer research in Canada. Just over half of that amount (51%) is not site-specific (meaning that the research is applicable to all cancers). The other half is allocated to specific types of cancers.

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

In truth, it doesn't. Some cancers are disproportionately underfunded, even given their higher incidence rate. Kidney cancer is proportionally and significantly underfunded by each of the following parameters:



- % of new cases
- % of deaths
- % of 10 year prevalence

The graph above shows a huge variance between cancer-specific funding. One might conclude that some cancers (such as breast cancer) receive vastly more funding than the % of cases or % of deaths would indicate. Other cancers (such as lung cancer) are vastly underfunded according to incidence and mortality rates.

Kidney cancer ranks as one of the cancers where funding is clearly not up to the levels that would be expected according to disease incidence.

To put it another way, if we calculate the total investment of research dollars per individual case, we see a stark contrast:

	Per New Case	Per Death
Breast Cancer	\$2440.75	\$9803.54
Kidney Cancer	\$519.80	\$1434.53

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MESSAGE FROM THE CHAIR

*Fellow patients, caregivers,
and friends,*

The start of every New Year gives me a chance to reflect on our past achievements and our new goals for the coming year.

2009 was a remarkable year for Kidney Cancer Canada in many aspects. One of our overriding objectives for last year was to become a registered charity so that we could give tax deductible receipts to donors and focus on a wider support base. We were very pleased to receive our charitable status in July. Thank you to all of you who have already made a charitable donation.

We were also very pleased to establish our Medical Advisory Board (MAB) consisting of many of the leading

experts in kidney cancer from right across the country. Our MAB includes leading medical oncologists, radiation specialists, uro-oncologists, a nurse, and a pharmacist. We are truly delighted with the tremendous support we continue to receive from the medical community.

I could not close this letter without thanking our Board of Directors for all their hard work this past year, particularly in working with the media to increase awareness for kidney cancer. What truly sets Kidney Cancer Canada apart is that we are all volunteers, and many of us are patients or caregivers ourselves. We thank each and every one of you for your role, whether you have responded to help another patient online or helped in another way. We couldn't do this without you.

As we look forward to 2010, we hope to meet you – whether online or in person at our patient meetings or our one-day patient education conference in April.

As we say at KCC...ONWARDS!

Tony Clark

Chair, Kidney Cancer Canada

FIND US ON:

facebook

Kidney Cancer Canada has a growing group on Facebook. You can find our Facebook page by logging in to Facebook and searching for 'Kidney Cancer Canada' or by clicking on the Facebook icon on the KCC home page.

You Tube

Kidney Cancer Canada has a YouTube channel. Check out our four new videos which provide stories of hope and inspiration for those fighting kidney cancer.

Find the channel at:

www.youtube.com/KidneyCancerCanada or by clicking YouTube icon on the KCC home page.

TREATMENT UPDATES

Afinitor Receives Health Canada Approval

Afinitor (everolimus, RAD001) received Health Canada approval in December 2009 for second-line treatment of mRCC following prior treatment such as Sutent or Nexavar. Afinitor will now be reviewed by the Joint Oncology Drug Review (JODR) and by the province of Quebec for recommendations for or against provincial reimbursement.

Revised Indication for Nexavar®

Nexavar® was approved for treatment of renal cell carcinoma (RCC) in 2006 under the Health Canada Notice of Compliance with Conditions (NOC/c) policy. Health Canada's conditional license for Nexavar® directed that a patient first had to have undergone (and failed on) cytokine treatment.

Health Canada has subsequently reviewed additional data and now supports the full approval of Nexavar® for mRCC. The revised indication is aligned with the current standard-of-care and permits the use of Nexavar® without specific pre-cytokine treatment. Cytokines are now seldom used, and have significant toxicity, with adverse effects of fatigue and flu-like symptoms, making these therapies less than ideal.

KCC is now seeking to have provincial funding reflect this important change and have the pre-requisite for cytokines removed in order for patients to access Nexavar®.

Currently in Clinical Trials:

Votrient (Pazopanib)
Axitinib
Avastin + Interferon (for mRCC)

Torisel Update:

Torisel is now publicly available in Saskatchewan in addition to B.C. and Nova Scotia. We need you to help us expand access in other provinces.

KIDNEY CANCER CANADA IS NOW A REGISTERED CHARITY

On July 8, 2009 Kidney Cancer Canada obtained registered charitable status. This terrific news means that we can now offer charitable tax receipts for donations to KCC.

We are the first and only organization in Canada created to provide education, information and support to patients and families dealing with a diagnosis of kidney cancer.

As you consider your charities of choice this year, please think of making a donation to Kidney Cancer Canada.

For more information on how to donate go to

www.kidneycancercanada.ca
and click on the 'Donate' tab

Charitable Registration #:
821670155 RR0001

ACCESSING VIDEO ARCHIVES OF KCC PAST PATIENT MEETINGS

It's as easy as 1,2,3.

Kidney Cancer Canada strives to reach and educate all patients, caregivers and medical professionals from across Canada regardless of where they live. One way we are able to do this is by recording our patient education meetings and then making them available for later viewing on our website.

Just follow these three easy steps to access the archives:

1. Become a member of Kidney Cancer Canada. Simply go to our website at www.kidneycancercanada.ca and click on 'Join Now'.
2. Once you have received your user name and password go to the 'Meetings' tab and click on 'Login to Live Webcasts and Past Meeting Archives'.
3. Click on the meeting you would like to view, login and start watching.

Please note that you will need a high-speed internet connection and speakers or headphones to see and hear the meeting.

(Cancer Research Funding - Continued from page 1)

Why the funding discrepancy?

Certainly we could suggest that, for many years, kidney cancer was one of the less attractive areas of research with few significant breakthroughs. However, in recent years, the kidney cancer community has 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.

Breast cancer has been referenced as a cancer that gets a larger funding complement than other cancers compared by incidence and prevalence. This is not to say that there should be less investment in breast cancer research. One only has to look at the tremendous advancements in breast cancer research to understand that there have been great returns on investment.

The ideal way to address disparities in funding is not to redistribute research dollars from more substantially-funded cancers to rarer, less-funded cancers, but to increase the overall funding for cancer, and direct new monies to underfunded cancers to level the playing field.

Where does this 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. For kidney cancer, 58% of all research funding comes from the voluntary sector (charitable vs. government).

Recognizing that public funding for cancer research is disproportionately allocated, we can see an opportunity for private funding to help level the playing field.

How can we increase the level of research funding in kidney cancer?

Certainly we want the best and brightest minds funded to conduct

UPDATE FROM YOUR DIRECTOR, MEDICAL RELATIONS

By Joan Basiuk - Director, Medical Relations

Kidney Cancer Canada Medical Advisory Board

Since its inception in June 2009, we have held two meetings by teleconference. The members of our MAB have helped our organization by reviewing recent health documents (Questions to Ask Your Health care Team and a Glossary) for our website. They have also authored a letter that was sent to the provincial reimbursement authorities advocating for changes to the reimbursement indications for Nexavar.

Representation at Recent Nursing Conferences

As your Director, Medical Relations, I had the chance to represent KCC at two recent Canadian nursing meetings: the Urology Nurses of Canada conference and the Canadian Association of Oncology Nurses conference. Posters were prepared for both of these meetings highlighting our organization. Many nurses took the opportunity to view our displayed posters and learn more about KCC.



research in kidney cancer. Over the long term, Kidney Cancer Canada hopes to raise charitable funds that will be specifically designated to support kidney cancer research. This year we became a registered charity in Canada so that we can grow our organization and also help to address the need for additional research dollars.

In the meantime, we can address this disparity in research funding by encouraging our healthcare providers to continue to apply for funding for kidney cancer research. We can also advocate for more research dollars for kidney cancer by writing to the government funding agencies to raise their awareness of the importance of kidney cancer research to our members.

As patients, caregivers, and healthcare professionals, we can all work together to raise the awareness of kidney cancer as a significant health issue that deserves its fair share of research funding.

*Written by Deb Maskens
Vice Chair, Kidney Cancer Canada*

¹ Canadian Cancer Research Alliance (2009). Cancer Research Investment in Canada, 2007: The Canadian Cancer Research Alliance's Survey of Government and Voluntary Sector Investment in Cancer Research in 2007. Toronto: CCRA.



INFORMED PATIENTS HAVE IMPROVED QUALITY OF LIFE **DAVE CHATTERS'** **STORY**

By Dave Chatters

I discovered I had Kidney Cancer the same way many other people do. In the fall of 1995, I noticed blood in my urine. My family doctor sent me for an abdominal ultrasound which identified a tumour on my right kidney. I was 49 years old, a non-smoker, a non-drinker, in good physical condition and as far as I know I was never exposed to any carcinogens. I had spent my life working outside ranching and working in oil and gas exploration. At the time I was diagnosed I had been elected to Parliament for 2 years. Who could have guessed politics was so toxic?

My doctor explained that the first-line treatment for renal cell carcinoma was surgically removing the affected kidney. After the surgery the doctor told me the tumour was contained within the kidney sac and the cancer had not spread. I was cancer free – at least I thought I was. Life returned to normal and I served as the Member of Parliament for Athabasca for 10 more years. During this time I had no follow up surveillance, which was often the norm for early-stage patients at that time.

In October of 2004 during a routine check-up I had an abdominal ultrasound. I was shocked to find out I had a tumour on my pancreas and my chest and several small spots on my lungs, all of which proved to be metastatic renal cell carcinoma. My oncologist told me there was no effective treatment and I had about six months to live.

I decided that I was not ready to give up yet and began researching what was out there in terms of diet, lifestyle and alternative treatments. At about that time Health Canada approved the first of a new class of drugs for trials in Canada. My oncologist offered me a spot in a sunitinib clinical trial. That was over 4 years ago and I am now one of the longest surviving patients to stay on Sutent without disease progression in Canada.

Today there are a number of different effective drugs available and many more being developed. Even for someone diagnosed with stage 4 kidney cancer there is great hope if one gets actively involved in their treatment. I would advise every patient to become informed about new drugs and treatments available and help map out your own treatment regime. I would also recommend that post-surgery patients insist on having regular follow up surveillance even if their disease appears to be contained to the kidney. Finally, I believe that everyone diagnosed with kidney cancer regardless of stage or grade should become a member of Kidney Cancer Canada so that they can become better informed about their disease and get support from fellow patients and caregivers.

Editor's note: Dave became involved as a volunteer with Kidney Cancer Canada two years ago and currently serves as our Director for Alberta.

KIDNEY CANCER PATIENT EDUCATION CONFERENCE

Saturday, April 10th, 2010

9:30 a.m. - 4:00 p.m.

CNIB Centre - 1929 Bayview Ave.,
Toronto

Open to patients, family members, friends
and medical professionals.

For more information go to:
www.kidneycancercanada.ca

RSVP to:

info@kidneycancercanada.ca
1-866-598-7166

KCC VOLUNTEER OPPORTUNITIES

Cancer Clinic Liaison

Individuals are required in every province for this volunteer role. The Liaison is responsible for distributing KCC print 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

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