



# NEWSLETTER

SPRING 2011

## Onward Fund for Kidney Cancer Research

*By Marianne Mulders, KCC Director of Fundraising*

In December 2010 Kidney Cancer Canada officially launched "Onward", our new – and very first – research fund for kidney cancer. Why "Onward"? Well, it has become our slogan here at KCC and one that was given to us by our co-founder Tony Clark who lost his own battle with kidney cancer on April 15, 2010. "Onward" has always symbolized our unwavering commitment to improving the quality of life for those living with kidney cancer and finding treatment innovation towards a cure, no matter the challenges that lie ahead.

The Onward Research Fund will provide an annual grant of \$55,000 to a research fellowship chosen by the Canadian Institute for Health Research through its Small Health Organization Partnership Program (SHOPP). Thanks to the matching grant funding available through SHOPP, Kidney Cancer Canada is responsible for raising half of that amount annually – \$27,500.

This research fellowship, named in honour of Tony Clark, will be awarded in the spring of 2011. Our research fundraising drive is in full swing and we are pleased to announce that ***we have secured the funding we need for our first research fellowship.***

We believe so passionately in the need for kidney cancer research that at our recent Board of Directors meeting we voted to ***fund a SECOND research fellowship commencing in 2012.*** While we know that this will mean added pressure on our small organization, we know it is what we must do.

Why is kidney cancer research so vitally important? To start, ***the rate of kidney cancer is on the rise.*** The incidence of kidney cancer in Canada has steadily increased by approximately 1.3% each year for both sexes since the late 1990s – and doctors don't know why. Unlike other cancers, no screening method is available and because kidney cancer is often symptom free, up to one quarter of newly diagnosed patients learn that their cancer has already spread to other parts of the body.

Research into kidney cancer is chronically underfunded – we must work to address the gap that exists between the incidence of kidney cancer in our country and the percentage of cancer research funds that are dedicated toward kidney cancer.

There has never been a more exciting time for kidney cancer research. Five years ago there was little hope for kidney cancer patients – it is a disease that is notoriously difficult to treat because it simply doesn't



respond to conventional chemotherapy. New treatment breakthroughs in the past four years have brought tremendous hope, but we need to go further. Cancer specialists believe that breakthroughs in the treatment of kidney cancer will have far-reaching benefits that will also improve the treatment of other cancers.

For more information about how to make a donation to Kidney Cancer Canada please visit us at [www.kidneycancer canada.ca](http://www.kidneycancer canada.ca) and click on "Donate" tab.

# Hi-Tech War Against Bone Metastasis: the Cyberknife

*By Benoit Bisson*

Let me start by giving you a bit of context. I was diagnosed with renal cell carcinoma (RCC) in July 2006. While it was originally thought to be in the early stages based on the size of the tumour (2.5 cm), scans showed there were three bone metastases; two on the 4th and 6th left ribs, and one on the right iliac bone.

To make a long story short, I spent the first two years on Nexavar, then two years on Afinitor (I was the first patient on it in Quebec, as part of a clinical research study). Since last December, I have been on Sutent. I had a left radical nephrectomy in 2007 and had my left adrenal gland removed by laparoscopy in 2010.

I didn't really need scans in November 2010 to tell me something wasn't right: the pain in my back was getting nasty, really nasty. Scans showed that the metastases on the ribs had grown, by a few millimeters, enough to reach my spine and wreak havoc with nerves, making me feel like someone was zapping me with 220V all the time. While my oncologist switched me to Sutent, I did what I've been doing from the start; research, more research, and then some more.

Not wanting to undergo any form of open surgery at this point, I focused on less intrusive techniques. Three stood out: the Cyberknife, a focused form of radiation therapy; cryosurgery, which freezes the target area; and radiofrequency ablation which uses radio frequencies to burn the tumours.

So, why did I opt for the Cyberknife? Quite simply because it is – in my opinion – the most advanced technology that can be used for the bone mets near my spine, with the least amount of risk. While it could not cover the entire metastasis, it could be used on the parts near the spine, both to reduce pain and (I hope) kill cancer cells and halt progression in that direction. Add to that the fact that Notre-Dame Hospital, in Montreal, is the leader in the field in Canada, with the latest model of Cyberknife. It's just my luck that it's located two blocks from where I live.

The procedure itself is very simple. First, a foam mould is made of the part of the body to be treated to hold the patient perfectly immobile during the procedure. Second, an MRI is done to have the image of the tumours to be treated that allows the programming of the Cyberknife by the radio-oncology team. Third, and last, are the treatments which can be between one and five interventions. In my case, it was three, with 75 high level shots of radiation each time.

What is impressive when you compare with regular radiotherapy is the lack of side effects. Even though the dosage is much higher, it is also highly targeted. Keep in mind that the first use of the Cyberknife



*Benoit Bisson and the Cyberknife.*

was – and still is – for brain tumours, and it deals with areas measured in millimeters. In my case, the only noticeable side effect was the fact I felt extremely tired following the treatments, and still do a couple of weeks later.

What I appreciate the most is the expertise and empathy demonstrated by the entire team at Notre-Dame Hospital. They are leaders in their domain,

and it's nice to see that such expertise is available right here, in Montreal, rather than having to go to the United States or elsewhere.

If you have additional questions, you can do searches in Google for 'cyberknife'. Feel free to drop me a line at [benoit.bisson@lebuzz.info](mailto:benoit.bisson@lebuzz.info) if you have any questions.

# Chair's Report



*Karen Ross, KCC Director of NB, Dr. Jennifer Knox, Deb Maskens and Dr. Georg Bjarnason at ASCO 2010*

## Looking Forward to a Great Year for KCC

Some of you will remember that KCC began with two patients sitting in a waiting room wondering why there was no information about kidney cancer in Canada. From those days long ago (ok, it was only 2006), this small band of patients has evolved into Canada's only registered charity focused exclusively on kidney cancer. It's pretty amazing to see how this group of two became four and then 12 and now is over 1,000 members strong.

With all that growth has come some changes for KCC. Hiring our first Executive Director, Tammy Udall, was a major step that has allowed us to do more across the country. Becoming a registered charity was yet another big leap for us and enables us to raise much-needed funds for research in Canada. In 2011, we will grow again by adding a new part-time Administrative Coordinator to better support patients, caregivers, and families in French.

Our volunteer Board of Directors continues to roll up their sleeves to challenge government decisions, review patient materials, and support our local patient meetings. We would not be where we are today without these committed volunteers who freely give their time to improve the lives of kidney cancer patients from coast to coast.

As we enter a new year for the KCC Board, I specifically want to welcome our two incoming Directors. First, with the retirement of Jolene Willacy who has been our Treasurer from the very beginning, we welcome Dan McCourt, C.A., to our Board as Treasurer. The position of Regional Director for Ontario will be filled by Dr. Nina Baluja, a Medical Oncologist with specific experience in the field of targeted therapies and kidney cancer. Both of these talented individuals will play a key role in moving KCC forward in 2011.

One of the key strengths of KCC has always been our close relationship with kidney cancer specialists across Canada. I would like to thank Dr. Jennifer Knox of Princess Margaret Hospital in Toronto, the inaugural Chair of our Medical Advisory Board for her leadership and strategic counsel. New as Chair of the Medical Advisory Board in 2011 is Dr. Scott North, Medical Oncologist from the Cross Cancer Institute in Edmonton.

This year is already off to a tremendous start. As always, if you have questions or suggestions, please give us a call, write us an email, or post on our website. We're here for you.

Onwards!

*Deb Maskens, Chair*

## Kidney Cancer Patients in B.C., Alberta, Saskatchewan and Ontario Now Have Access to Second-Line Therapy

Effective Feb. 1, 2011 the public drug programs in British Columbia, Alberta and Saskatchewan will fund everolimus (Afinitor) for the treatment of advanced renal cell carcinoma after failure of a first-line tyrosine-kinase inhibitor therapy such as sunitinib, or sorafenib (or both). On February 18th, KCC was informed that Ontario will also fund Afinitor through the Exceptional Access Program.

Afinitor represents the first Health-Canada approved treatment option for patients whose cancer has progressed despite prior targeted therapy with Sutent or Nexavar. Access to Afinitor via the manufacturer's AfiniTRAC Reimbursement Support Program officially ended to new patient enrolment on January 31, 2011. Patients enrolled in this program prior to and including January 31, 2011 will continue to receive their treatment through the AfiniTRAC Program.

Kidney Cancer Canada has been working extremely hard to ensure that patients are able to access sequential therapies such as Afinitor. KCC congratulates the governments of British Columbia, Alberta, Saskatchewan and Ontario for improving drug treatment access for kidney cancer patients, and urges all other provinces to fund Afinitor for the treatment of kidney cancer.

Our elected representatives and other government decision-makers need to know that kidney cancer patients desperately need options beyond first-line treatment. KCC continues to urge our members to work together to make sure that we don't have patients falling between the cracks and left without funded treatment options. Please visit [www.kidneycancercanada.ca](http://www.kidneycancercanada.ca) and click on "Join the Fight" to find out how you can help us advocate for access to Afinitor in the remaining provinces that have not yet funded sequential treatment options for kidney cancer patients.

## Treatment Updates

Five treatments for advanced kidney cancer have been approved by Health Canada. These treatments include:

1. Nexavar/sorafenib
2. Sutent/sunitinib
3. Torisel/temsirolimus
4. Afinitor/everolimus
5. Votrient/pazopanib

For details on how you can access each of these treatments in your province, including news about Patient Access Programs, please visit our website under News/Drug Access News.

## Clinical Trial Updates

Clinical trials can provide an important opportunity for patients to access new therapies. KCC provides an easy-to-use reference that lists clinical trials for kidney cancer according to stage of disease (whether pre-surgery, post-surgery, or advanced stages). This document is updated monthly with new clinical trials. Please see our website under [Resources/Clinical Trials](#).

# Announcing an Award of Excellence in Kidney Cancer Nursing

By Joan Basiuk, R.N.

KCC is thrilled to announce the establishment of an endowed nursing award in honour of our founder, Tony Clark. Beginning in 2011, Kidney Cancer Canada will sponsor an annual award through the Canadian Association of Nurses in Oncology/ Association canadienne des infirmières en oncologie (CANO/ACIO). This Award of Excellence has been created to honour the legacy of Tony Clark, our co-founder and Chair from 2006-2010, and to recognize the role of nurses in the care of kidney cancer patients across Canada.

As one of Tony Clark's nurses, I can certainly say that Tony was an inspiration to everyone involved in his care. Every nurse assigned to Tony's care was influenced by treating a patient who embodied optimism throughout his journey with the disease. With the knowledge of new treatment options, he educated nurses about the new hope in kidney cancer and became a living testimonial to that hope, translating a dire prognosis of one year to over

five years of quality living. Tony knew every nurse by name and they knew him, his family and the charitable organization that he created and was so proud of, Kidney Cancer Canada.

To honour Tony's memory, this award will be given to an individual or group of CANO/ACIO nurses to acknowledge the exceptional difference that they make to the lives of kidney cancer patients. Each year, this award will be presented to the chosen recipient at the annual CANO/ACIO conference.

Kidney Cancer Canada would like to extend our sincere gratitude to GlaxoSmithKline, Novartis Oncology and Pfizer Oncology for the generous support that has allowed us to make this award possible.

We would also like to encourage nurses across Canada to apply for this award. This year's deadline for nominations is June 1, 2011.

More information can be found at:  
[www.cano-acio.ca/lectureship\\_awards\\_2](http://www.cano-acio.ca/lectureship_awards_2)



Tony Clark

## 2011 KCC Calendar of Events

- ▶▶▶ Kidney Cancer Canada Patient Education Conference  
***Kidney Cancer – You and Your Support Network***  
Saturday, April 16th, 2011  
9:00 a.m. – 4:00 p.m.  
Canada Olympic Park  
ATCO Centre  
Calgary, Alberta
- ▶▶▶ Montreal – May  
***Patient information meeting and live webcast (French)***
- ▶▶▶ Halifax – June  
***Patient support group meeting***
- ▶▶▶ Ottawa – September  
***Patient information meeting and live webcast***
- ▶▶▶ Vancouver – October  
***Patient meet and greet***
- ▶▶▶ London – November  
***Patient information meeting and live webcast***
- ▶▶▶ Other support and information meetings are also being planned in: Newfoundland and Labrador, New Brunswick and Saskatchewan for 2011

To stay informed of exact meeting dates in your area, please register on the KCC website by clicking on the [Join Kidney Cancer Canada](http://www.kidneycancercanada.ca) link.

Register for all meetings online at: [www.kidneycancercanada.ca](http://www.kidneycancercanada.ca) or by calling 1 866 598 7166

## Announcing the Kidney Cancer Canada Nurses' Network (KCCNN)

By Joan Basiuk, R.N.

By launching the Kidney Cancer Canada Nurses' Network (KCCNN), our goal is to provide Canadian nurses with additional tools and knowledge to better care for patients with kidney cancer. The aims of the KCCNN are to connect, educate, support and provide opportunities for collaboration with other nurses practising in the field of kidney cancer.

Through the use of a private website with access restricted to its members, the KCCNN will become a national resource for nurses, nursing students and other healthcare professionals working in the field of kidney cancer. Created by nurses for nurses, this online resource will identify and discuss issues relevant to RCC nursing. This new resource will help nurses to share tips and tricks from their experience with patients, research ideas, and view important journal articles and educational opportunities.

Development of the Kidney Cancer Canada Nurses' Network is now underway. Our plan is to showcase the network at the annual conference of the Canadian Association of Nurses in Oncology (CANO) in September 2011.

Kidney Cancer Canada would like to thank Pfizer Oncology for their generous support of this exciting new project.

## Nursing Students Build Awareness About KCC

KCC is proud to support the recently-formed Student KCC Chapter at Memorial University of Newfoundland. Thank you to all of the nursing students who are working with us to build awareness in NL.

# Update on the 2011 Canadian Kidney Cancer Forum



*Attendees of the 2011 Canadian Kidney Cancer Forum.*

*By Joan Basiuk, KCC Director, Medical Relations*

Were you wondering where your favourite kidney cancer specialist was from January 20-22, 2011? Chances are that he or she was attending the 3rd Canadian Kidney Cancer Forum (CKCF) at the Kingbridge Conference Centre, just north of Toronto. Attendees came from across Canada and included urologists, medical oncologists, pharmacists, radiation oncologists, radiologists, and nurses, all who specialize in kidney cancer. Kidney Cancer Canada's volunteer board was invited to attend this year to provide input from the patient's perspective. Michael Atkins, a medical oncologist from the Beth Israel Deaconess Medical Center's Cancer Center in Boston, and Robert Uzzo, a uro-oncologist from Fox Chase Cancer Center in Philadelphia were the guest lecturers.

The meeting was called to update the Canadian Consensus Guidelines for kidney cancer. These guidelines are published in the CUAJ (Canadian Urological Association Journal) and become the blueprint for the management of kidney cancer from diagnosis, to follow-up care, to advanced disease. The last edition of the Consensus Guidelines was published in 2009, so it was time for an update based upon new research, new knowledge, and new treatments available. You can find these guidelines on the Kidney Cancer Canada website in the '[Resources](#)' section.

Another objective for the meeting was to further develop the Canadian Kidney Cancer Information System (CKCis). After obtaining consent from patients, coordinators for the database project will be collecting information on patients with kidney cancer at centres across Canada. This information will help Canadian kidney cancer specialists learn more about this disease and its treatment. Watch for more on this exciting project in the coming months.

Survivorship was the theme for a one-day conference that was held prior to the forum and involved patients and medical specialists from the bladder, kidney, prostate and testicular cancer communities. At the Kidney Cancer Forum, Dr. Christina Canil, a medical oncologist from Ottawa, summarized the proceedings from that meeting and gave a presentation on the development of a survivorship action plan specifically for kidney cancer. Our vision is that every patient will eventually be given a personalized survivorship care plan. Stay tuned for more information on this topic.

New at this year's Forum was the 1st Canadian Kidney Cancer Floor Hockey Championship game. After donning their jerseys and picking up their sticks, the "Med Oncs" (the medical oncology team) faced off against the "Scalpels" (the urology team). No one is quite sure who won the game, but much fun was had by the players and spectators alike.

Overall, the Canadian Kidney Cancer Forum was an extremely productive and informative meeting. Watch for the posting of the updated Canadian Consensus Guidelines on the KCC website in the near future.



*Dr. Lori Wood, Med-Onc Team*



*Dr. Michael Jewett, Scalpels Team*

# The Onward Research Fund – How You Can Make a Difference



Sophie

We are thrilled that so many friends of Kidney Cancer Canada come to us asking how they can support the work we do and our research efforts. There are a number of ways that you can make a difference. Here is just one example of how one of our friends has helped.

On July 18th, 2010 Effie Theofilaktidis hosted a BBQ with family and friends in honour of her mother Sophie Karandinakis. Effie's mother was in a courageous battle with kidney cancer and wanting to help raise money for research, Effie volunteered to have her head shaved as a fundraiser for Kidney Cancer Canada. Amazingly, what began as a simple barbeque raised over \$12,000 for kidney cancer research.

Sadly, Sophie passed away on August 19, 2010 but her memory and spirit will live on in the lives of those who will benefit from the research. Kidney Cancer Canada would like to thank Effie and everyone who made this touching event such a huge success.

Every donation, and all proceeds from fundraising events for KCC, goes towards supporting vital kidney cancer research. With the help of Effie and many others over \$80,000 was raised in 2010 to support this cause.

In 2011 we will continue our efforts to raise even more money towards supporting kidney cancer research.

Here are some ways that you can help:

- 1 Make a personal donation** – Each and every donation, no matter how big or small, makes a difference. To make a donation go to [www.kidneycancercanada.ca](http://www.kidneycancercanada.ca) and click on the 'Donate' tab.
- 2 Ask your employer to make a donation** – Some employers have programs that match the personal gifts made by employees by simply filling out a form. Many employers also have a charitable fund whereby they can make contributions to a charity on the request of their employees.
- 3 Make a tribute** – Are you having a special birthday or anniversary in the near future? Ask your guests to make a donation to Kidney Cancer Canada in lieu of bringing a gift. Instead of giving out party favours at your wedding, notify your guests that you have made a donation to KCC instead.
- 4 Organize an event** – If you are interested in organizing a fundraiser with proceeds benefitting Kidney Cancer Canada, please give us a call or send an email to discuss your event plans. It need not be a big event. Even the simplest occasions can help support research – consider a garage sale, a bake sale, a car wash or your own personal walkathon... together we will make a difference, one step at a time.

Kidney Cancer Canada  
has adopted the:



## 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](mailto:info@kidneycancercanada.ca)

1-866-598-7166

## Quick Tip

### ***Less is More – Saving Kidney Function While Still Effectively Treating Your Kidney Cancer***

For a patient diagnosed with early stage kidney cancer, the first and most important consideration is to remove the tumour. However, in recent years it has become known that in some select groups of patients with localized kidney cancer, it is equally vital to save as much kidney function as possible. These kidney-sparing treatments should be considered for patients with:

- tumours that are less than or equal to 4 cm. in diameter (and may even be considered for some select larger tumours),
- other diseases that can threaten kidney function (such as diabetes, high blood pressure) and/or
- decreased kidney function already.

Your urologist has several options (partial nephrectomy rather than complete or radical nephrectomy, cryoablation, radiofrequency ablation, active surveillance) that may be suitable for the treatment of your kidney cancer that also help to preserve as much kidney function as possible for the future.

**If you are diagnosed with kidney cancer, make sure to educate yourself and ask your physician the right questions about what treatment option is right for you. Visit [www.kidneycancercanada.ca](http://www.kidneycancercanada.ca)**