



**Kidney
Cancer
Canada**



NEWSLETTER

SUMMER 2010

ADVOCATING FOR YOUR LIFE

It started with a voice mail.

On April 19, 2010, John Kinnear left a voice mail at the Kidney Cancer Canada office. He said that he was a patient and that his medical oncologist, Dr. Georg Bjarnason from Toronto's Sunnybrook Regional Cancer Centre, recommended that he contact KCC. John had applied for out of province treatment from the Ontario Government, but had been denied. He was calling for help.

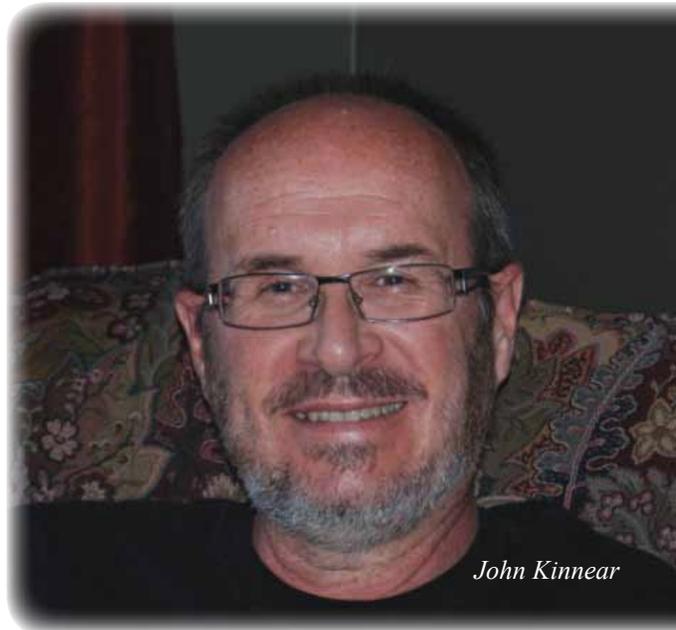
A 56 year old high school teacher of science and chemistry from Aurora, Ontario, John first noticed blood in his urine and felt some discomfort this past January. He went to the hospital as the pain started to come in waves. Within a day, he had the results of a CT scan showing a growth on his right kidney. Surgery took place in March. When John and his wife Janette met with Dr. Bjarnason later that month, they were given the news – clear cell renal cell carcinoma, that had spread to his lungs.

The only treatment that could cure John was HD IL-2. Interleukin-2 is a type of protein called cytokine and when given in high doses, is supposed to help the body's own immune system destroy the cancer cells. John was told that he was a good candidate for the treatment, but that it was not funded in Ontario. Dr.

Bjarnason applied through the Ontario Health Insurance Plan (OHIP) for John to go out of province for the treatment, but that request was declined in a letter received April 9. That's when John reached out to KCC.

With the guidance and support of KCC, John and Janette took on the role of advocates for John's care. They sent a Notice of Appeal to the Ministry of Health and Long-Term Care, stating very clearly that they did not accept the decision of OHIP. They met with their Member of Provincial Parliament, Frank Klees, who contacted the Office of the Minister of Health and Long-Term Care and helped to get them an expedited hearing.

On May 6, John and Janette participated on a pre-hearing teleconference with OHIP. They presented a position paper from Dr. Bjarnason in support of HD IL-2 treatment, along with evidence of improved results for patients. The representative from OHIP stated that Cancer Care Ontario's June, 2006 guidelines deemed HD IL-2 as experimental and therefore no funding could be provided. When Janette raised



John Kinnear

the question of how many people in Ontario had received funding for HD IL-2 treatment since June, 2006, the OHIP representative did not know. The facilitator asked the representative to find out the answer before their next hearing on May 31.

John immediately went back to KCC to find out if they could put him in touch with a patient in Ontario who had applied for and been granted out of province coverage for HD IL-2 treatment. They did, and after forwarding this information to OHIP, on May 27 John and Janette got the news they'd been hoping for – the government would fund him to receive HD IL-2 outside Ontario.

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MESSAGE FROM THE CHAIR

A Tribute to an Inspirational Patient and Good Friend

It's hard to speak about Tony Clark without using the word inspiration. Despite his passing from papillary kidney cancer in April 2010, Tony's influence on Kidney Cancer Canada continues with everything we do.

When the phone rings and a new patient comments "Now I know that I'm not alone in this."; When a patient writes on our Discussion Forum "Thank you for this site and all of the information here."; When a new treatment is approved and we begin our advocacy efforts; we know that Tony Clark made all of those moments possible.

Back in 2005 when Tony was first diagnosed, there was no KCC. No network of patients. No Canadian website. No patient voice in Canada. Tony and his wife Sharon did their own

research and sought expert advice. Later they would comment that they had felt completely alone in their journey with metastatic renal cell cancer.

I had the pleasure of meeting Tony in a waiting room in January 2006. He was the first patient I had ever met. Instantly we began to share notes and offer each other support. As a business executive, Tony could see the need for something much bigger...

Fully bilingual and with the grace and charm to fill a room, Tony was the natural leader of Kidney Cancer Canada. Despite his own challenges with metastatic disease, he continued to

offer hope to new patients and to focus his energies on improving the situation for other patients across Canada.

As the new Chair of KCC, one of my most heart-felt goals in this next year will be to find ways to honour Tony. To begin, we will name our first research fellowship in kidney cancer in his honour. Tony's legacy in building KCC will be forever remembered. Tony, you changed our world. Thank you.

Deb Maskens

(Advocating - continued from page 1)

"My advocacy efforts worked for a number of reasons," says John. "First and foremost was having my wife Janette as a partner in the work, but reaching out to Kidney Cancer Canada was also critical because they helped me prepare questions and statements before every meeting, and really stay focused on the objective. Along with Dr. Bjarnason, I was surrounded by a tremendous team of family, friends and supporters that made all the difference."

In just 38 days, from his initial voice mail to KCC through to a positive decision from OHIP, John Kinnear learned how to advocate for his care. But he's come to see his work as unfinished. "Why did I have to go through this? Why was this treatment not covered in the first place? It's time to work together to get HD IL-2 covered in Ontario for all kidney cancer patients who may benefit."

Your Health...

QUICK TIP

Patients with kidney cancer often experience episodes of fatigue. The fatigue may be caused by their cancer, as an aftermath of their surgical procedure or it may be a side effect of one of the medical treatments.

Currently, there are numerous research projects focusing on the use of exercise to combat the fatigue experienced by cancer patients. An article in a recent issue of Cancer Research Update from the American Institute for Cancer Research stated that "physical activity boosts quality of life for cancer survivors".

Start out with a short walk each day and gradually increase the distance you go and the speed you travel. A pedometer is a great tool to help with your motivation. Challenge yourself to increase the number of steps gradually each day.

Heather Gage, RN, QEII Health Science Centre in Halifax states "We discuss managing fatigue by doing activities in moderation and to rest when tired, it's normal and it's okay to feel this way. But, most importantly, do activities that you love. It gives a good feeling and it's the little things that matter most."

TREATMENT NEWS

►►► Torisel (Temsirrolimus) Funded in Ontario

Effective June 14, 2010 Torisel will be funded in Ontario under the Ministry of Health and Long Term Care / Cancer Care Ontario's new Drug Funding Program as a first-line treatment for mrcr patients with poor prognosis (including non-clear cell histology).

►►► Health Canada Approves Votrient (Pazopanib)

Health Canada has approved Votrient (pazopanib) for metastatic renal cell carcinoma. According to the Health Canada announcement, the Notice of Compliance (NOC) states that pazopanib has been approved for first-line treatment of metastatic clear cell renal cell carcinoma, or second-line treatment following cytokine therapy (such as Interferon or Interleukin).



KIDNEY CANCER TREATMENT OPTIONS GROW BUT BARRIERS TO ACCESS REMAIN

BY ROBERT BICK & DEB MASKENS

Health Canada has now approved five targeted therapies for the treatment of renal cell carcinoma. Those medications are: Afinitor, Nexavar, Sutent, Torisel and Votrient. Research has demonstrated that overall survival and quality of life for patients with kidney cancer can be improved through sequential use of these treatments. However, in Canada, patients only have access to only one of these therapies through their public drug programs.

Patients and physicians investigating second-line treatment options and access for metastatic kidney cancer should be aware that on January 20, 2011, the manufacturer-sponsored reimbursement support program for Afinitor will no longer be available to new patients. This means that your access to Afinitor will depend on whether or not your province has decided to reimburse this drug (if you are eligible for your provincial pharmacare program) or whether you have private drug insurance that includes coverage for Afinitor, or have enough private funds to cover the cost of the drug yourself.

Afinitor represents the first Health Canada approved treatment option for patients whose cancer has progressed despite prior targeted therapy with Sutent or Nexavar. We need to work to ensure that all patients have the ability to access a second-line therapy such as Afinitor. Our elected representatives and other government decision-makers need to know that we desperately need Afinitor accessible through public-funding. If we work together, we can make sure that we don't have patients falling between the cracks and left without funded treatment options. Please visit www.kidneycancercanada.ca, follow our **blog**, and click on **"Join the Fight"** to find out how you can help improve drug treatment access for kidney cancer patients.

KIDNEY CANCER CANADA 1ST ANNUAL PATIENT EDUCATION CONFERENCE

BY JOAN BASIUK



Tammy Udall & Dr. Jennifer Knox

On Saturday, April 10th, Kidney Cancer Canada hosted its first Patient Education Conference in Toronto. Despite the sunny weather

on this warm spring day, approximately 160 people joined us in the conference room to listen to the presentations and connect with one another. Participants came from as far away as Victoria BC and Fredericton, NB, showing us that KCC is truly a national organization.

The day got off to a good start with a humorous but insightful presentation from our keynote speaker, Dr. Robert Buckman. He convinced all of us in attendance that cancer is indeed a word, not a sentence.

The presentations covered a range of topics on both the current surgical and medical treatment of kidney cancer as well as

treatments that are now in clinical trials. A panel of speakers discussed the management of the side effects of treatment and gave the audience many helpful tips. Our presenters for the day were renowned specialists in the treatment of kidney cancer.

Two patients with kidney cancer, Heather Pugh and Stephen Andrew, allowed us to have a glimpse into their journeys with this disease. Their messages to us, while very realistic, were uplifting and full of hope.

As two of our members who attended the conference so eloquently put it:

"The information acquired at the conference allowed "the patient" to ask questions of his

oncologist that would never have occurred to him before. As well it gave him the confidence to ask the questions."

"To have the opportunity to gather with others with similar experiences helps alleviate the loneliness of the journey."

Thanks to the helping hands of many volunteers and our planning committee, this conference was a resounding success. We hope to see all of you at next year's conference!

For anyone who missed the conference or attendees who want to refresh their memories, video of each of the presentations is available on the KCC website at: www.kidneycancercanada.ca



Photos courtesy of Nick Basiuk Photography



WHY I GOT INVOLVED WITH KIDNEY CANCER CANADA

MARION'S JOURNEY

By Marion Cooper

In January 2006, at the age of 36, I was enjoying life with a new baby and adjusting to new routines after maternity leave and returning to work. I felt very tired but attributed it to the sleep deprivation that all new parents experience. Overall I was feeling healthy. It wasn't until I noticed blood in my urine one day that alerted me I should see my doctor. After an abdominal ultrasound I was told there was an 11 cm tumour on my left kidney that appeared consistent with kidney cancer. Shortly after my diagnosis I had an open radical nephrectomy successfully removing the 11 cm tumour which was contained to the kidney. Later, pathology reports confirmed that the tumour was a rare chromophobe renal cell carcinoma and there was no evidence of the disease having spread.

Since January 2006 I continue to get regular follow-up by a uro-oncologist. I feel extremely grateful that the tumour had not spread outside the kidney but I am also aware of the need to have regular follow-up so that if there is a recurrence I will be able to deal with it early.

Following my surgery I recognized the importance of becoming more informed about the disease and what treatments might be available if it became metastatic. I quickly learned that treatment options were limited and that kidney cancer was very different than other types of cancer. I sought out support from the local CancerCare organization hoping to meet others with a kidney cancer experience who could provide mutual support. It wasn't until the spring of 2008 when I discovered the newly established Kidney Cancer Canada (KCC) website that I made a connection with other kidney cancer patients. This moment was life changing. I no longer felt isolated with this disease experience. It was amazing to finally meet other kidney cancer patients, share experiences and information and encourage one another.

I became actively involved with Kidney Cancer Canada following the first Kidney Cancer Canada patient education evening in September 2008 in Winnipeg. In November 2008 I joined the KCC Board as the Manitoba Director. I have been involved in a number of media awareness and public education activities on behalf of KCC, sharing my story and speaking about the importance of good follow-up and advocating for drug access.

I live in Winnipeg with my spouse Heather and our young son Carter. I feel my experience as a kidney cancer patient has given me a greater appreciation for life, my family and friends. It has also taught me that when I have a health issue I need to be actively involved in understanding my condition and what treatment options are available so that I can advocate for my own best care!

I believe there is always a silver lining in any life crisis or health problem. There have been many silver linings for me...having the opportunity to be involved with Kidney Cancer Canada is just one of them!

FALL 2010 PATIENT EDUCATION MEETINGS

Sep. 21 ▶▶▶ Quebec City
Nouveaux développements dans la prise en charge du cancer du rein
With Dr. Louis Lacombe and Dr. Éric Levésque

Oct. 25 ▶▶▶ Hamilton
Recent Advances in the Management of Kidney Cancer
With Dr. Sebastien Hotte and Dr. Anil Kapoor

Nov. 29 ▶▶▶ Vancouver
Updates in Kidney Cancer Treatments and Management of the Side-effects
With Dr. Christian Kollmannsberger, Dr. Peter Black and Susan D'Aloisio, R.N.

Dec. 1 ▶▶▶ Edmonton
Living Well on One Kidney
With Dr. Ron Moore and Dr. Branko Braam

All meetings run from
 7 - 9 p.m.
 (Meet and greet starts at 6:30 p.m.)

For more information go to:
www.kidneycancercanada.ca
 ▶▶▶ **RSVP to:**
info@kidneycancercanada.ca
 1-866-598-7166

DONATE

TO KIDNEY CANCER CANADA

Kidney Cancer Canada is a registered charity. Donations help to educate patients about kidney cancer, provide support to patients and families, advocate for equal access to treatments and fund much-needed kidney cancer research.

Make your donation at:

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

or Mail your cheque to:

Kidney Cancer Canada
 P.O. Box 23026, Westgate P.O.
 Cambridge, ON N1S 4Z6



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