



The Case for Kidney Cancer Survivorship Plans

By Deb Maskens, Chair Kidney Cancer Canada

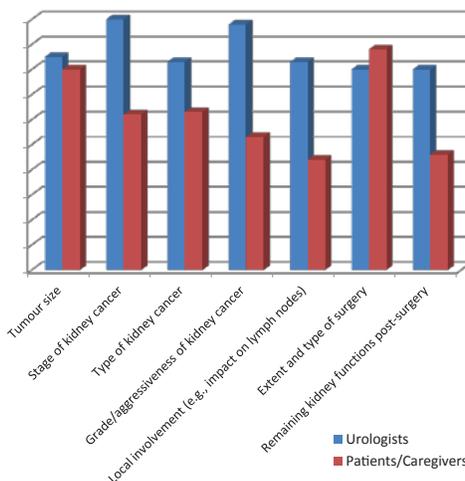
Whether you were diagnosed with kidney cancer last week, three years ago, or more than a decade ago, chances are that you were initially shocked at the diagnosis and then pleased to have the initial treatment, usually surgery, over and done with. For up to 75% of patients diagnosed this year in Canada at Stages 1, 2, or 3, surgery will be the only treatment they require. Chances are that their surgeon (urologist) said something that sounded like “I got it all” and then, for many, the rest of the information given was blurred in a tremendous haze of relief.

Across Canada we often meet patients who have questions about their health after kidney cancer surgery. We noticed that many did not remember key elements of their diagnosis: the type of kidney cancer, the stage, the grade, their risk for recurrence, or non-cancer related health effects.

And so, we explored the idea of a survey to find out what patients and caregivers are told (or remember being told) and what information today’s urologists are indeed sharing. We knew we would need help to do such a study, so we discussed the proposal with physicians and sponsors and were happy when Pfizer Canada offered to provide funds for us to hire a market research company, Leger Marketing, to conduct the study across Canada in both languages.

Thank you to each and every one of you who filled out the survey (all 321 of you!) We also surveyed 40 urologists from coast to coast. The results show three major areas of disconnect between information that is given today (most often verbally) – and information that is actually remembered by patients and caregivers.

1. The Disconnect in Information Given Post Surgery



2. The Disconnect in Information About Long-term Health Outcomes

Our study revealed an even greater disconnect when it comes to information given to patients and caregivers about any long-term impacts of the kidney cancer surgery:

Possible Health Outcomes Due to Kidney Cancer Surgery	Patients & Caregivers Recall	Urologists Provide
Risk that my kidney cancer might recur in the other kidney or elsewhere	42%	93%
Increased risk of hypertension (high blood pressure)	15%	73%
Increased risk of chronic kidney disease	16%	83%

3. The Disconnect in Physical, Psychological and Emotional Concerns

The majority of patients/caregivers admitted to dealing with physical (56 per cent), psychological (52 per cent), and emotional (71 per cent) impacts as a result of their experience with kidney cancer. Fully half of patients/caregivers (51 per cent) said they were not prepared to deal with these concerns.

Interestingly, urologists significantly under-estimated the extent of these issues estimating that only about a third of their patients experience physical (31 per cent), psychological (33 per cent), or emotional (31 per cent) impacts.

So Where Do We Go From Here?

During National Kidney Month (March), we began to get the word out across Canada that kidney cancer patients need written survivorship plans. In June this year we will take our study to the Canadian Urology Association (CUA) conference in Alberta. In the long-term, we hope to partner with the Kidney Cancer Research Network of Canada to develop individualized survivorship plans for ALL patients diagnosed with kidney cancer.

- Read our “Top Ten Tips” for Kidney Cancer Survivors on page 3.
- For a full summary of the survey findings and our National Kidney Month Press Release, visit our website at www.kidneycancer.ca and click on the ‘News’ tab.



THANK YOU!

By Catherine Madden, Executive Director

April 15th-21st, 2012 is National Volunteer Week across Canada. On behalf of the volunteer Board of Directors and Maryse Tremblay, our Coordinator, I extend our thanks and appreciation to each and every one of you for your gifts of time and enthusiasm. We couldn't do it without you.

Kidney Cancer Canada is the sum of its parts... our volunteers who give so much of their time, talent and passion, the patients and caregivers who we support and who give back exponentially in so many different ways, the healthcare professionals who care for those affected by kidney cancer and share our resources... working together, we will make a difference and ensure that we improve the lives of everyone touched by kidney cancer.

One of my favourite quotes by Margaret Mead really speaks to this amazing organization, founded just 5 years ago by patients, for patients... "Never doubt that a small group of thoughtful, committed people can change the world. Indeed, it is the only thing that ever has." Kidney Cancer Canada is stronger because of YOU. Kidney Cancer Canada is making a difference because of YOU. Kidney Cancer Canada is changing the lives of those affected by kidney cancer because of YOU.

We value your time... If you are interested in getting involved with Kidney Cancer Canada there a variety of opportunities from peer-to-peer support to joining one of our working committees.

We value your support... every donation made to Kidney Cancer Canada makes a difference and is put to work advocating for access to treatments, providing support and information, and increasing awareness of kidney cancer as a significant health issue.

We value your feedback... What are we doing right? What could we be doing better? We're here and we're listening.

St. Patrick's Day Fundraiser for Kidney Cancer Canada

"Shortly after spring break I decided to launch a fundraising initiative here at the University of Western Ontario to raise awareness for Kidney Cancer Canada. With the colour green representing Kidney Cancer I thought St. Patrick's Day would



be the perfect occasion to print t-shirts and sell them for donations. I was expecting to raise a few hundred dollars selling these t-shirts to my close friends, so I put together a quick Facebook group to spread the word and organize orders. The word spread quickly and before I knew it, hundreds of orders flew in. I was astonished at the support I received, and willingness of friends, classmates, and strangers to support KCC. Before St. Patrick's Day I sold out of shirts, yet donations were still coming in. In total I raised just over \$2000 in 2 weeks. If I knew how easily this could be done, I would have begun fundraising efforts like this years ago. I hope others realize that it doesn't take a hero, but anyone can put together a simple fundraiser and together it really will make a difference. I feel so fortunate that I found this out for myself, and had a great time doing it. While out celebrating St. Patrick's Day it was amazing to see so many of my shirts being worn, and over 300 bracelets on the wrists of supporters helping raise awareness for Kidney Cancer Canada.

- Arlene Miron, Student and daughter of patient Dale Miron, University of Western Ontario

Fraternal Order of Eagles Ladies Auxiliary #3097, Campbell River, B.C.



The Muir daughters dress-up night, Debi in white, JoAnne in black.

Every year the Eagles Ladies Auxiliary designates funds for a charity. Thanks to member Dorothy (Dot) Muir, mother and caregiver of kidney cancer patient JoAnne Muir, the chosen charity this year was Kidney Cancer Canada.

One of the ladies in the Auxiliary donated money from catering she had done in the amount of \$2,000.00. The Eagles ladies also hosted raffles and a \$5.00 spaghetti night. While having fun making everything from soups to meat pies, the Eagles set a goal of raising \$5,000.00 by December 2011. We are delighted to report that their grand total was \$5,227.00! (Funds were equally matched by our research program resulting in over \$10,000.00 in kidney cancer research!)

Kidney Cancer Nursing Student Chapter - Newfoundland

Kidney Cancer Canada Board Member Dan Mosher had the opportunity last fall to share his story with a group of fourth year nursing students, many who have now joined the Newfoundland Kidney Cancer Nursing Student Chapter. The group has held a variety of fundraising events including a pot luck meal, movie night and their first-ever bake sale that raised \$226.00 for Kidney Cancer Canada. There is a great deal of enthusiasm within this group to raise funds and create awareness while enjoying the opportunity to network and have fun!



2012 Bill Dompierre Memorial Basketball Tournament, Nova Scotia

The 3rd Annual Bill Dompierre Memorial Basketball Tournament was held January 13th & 14th, 2012 at Lockview High School in Nova Scotia and serves as a wonderful opportunity to remember and honour a great husband, father, friend, and Coach who was loved by everyone who knew him. Bill was a players' coach – his players loved him and he loved them. Well respected around the league by his coaching peers, there was nothing he loved more than being in the gym. The Bill Dompierre Memorial Basketball Tournament serves as a great way to raise awareness and funds for others living with kidney cancer through competition, sportsmanship and memories! Congratulations to the organizers and participants for raising \$5000.00 for kidney cancer research at this year's event!



January 13th & 14th, 2012

We need you! How can you help?

Make a personal donation – every donation counts and is put to work advocating for access to treatments, providing support and information, and increasing awareness of kidney cancer as a significant health issue.

Ask your employer to make a donation – does yours have a matched gift program? Many companies will match your donation dollar for dollar.

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The 2012 Kidney Cancer Canada Board of Directors



Board of Directors in order as seen in photo from left to right. . . **Catherine Madden**, Executive Director • **Deb Maskens**, Chair • **Marion Cooper**, Vice Chair, National & Director, Prairies • **Joan Basiuk**, Vice Chair, Operations & Director, Medical Relations • **Robert Bick**, Director, Communications • **Bonny Beswick**, Secretary • **Marianne Mulders**, Director, Fundraising • **Dale Miron**, Director, Membership • **Nicole Giroux**, Director, Quebec • **Dan McCourt**, Treasurer • **David Chatters**, Director, Western Canada • **Maryse Tremblay**, Coordinator • **Wally Vogel**, Director, IT • **Dr. Nina Baluja**, Director, Ontario • **Karen Ross**, Director, Eastern Canada • Absent: **Dan Mosher**, Director, Newfoundland and Labrador

Thank You Endeavour

By Catherine Madden, Executive Director

On behalf of Kidney Cancer Canada, our Board, our staff, and all of the people we serve, thank you to Endeavour Volunteer Consulting for Non-Profits (Endeavour) for working with us to develop our Five Year Strategic Plan.

Endeavour is a non-profit organization that provides pro-bono professional management consulting for non-profit groups. Since its founding in 2007, Endeavour has recruited and managed more than 200 volunteers to provide management advice to 31 non-profits in Ontario. These client organizations help communities in many areas, such as the arts, children and family services, disabilities, education, environment, healthcare, immigrant services, rural development, skills training, poverty relief, and youth development.

Kidney Cancer Canada applied to engage with Endeavour knowing that, as we approached our five year anniversary, we needed to take a strategic look at our

organization and develop a plan for moving forward. After many hours of consultation and a successful two-day meeting with the team from Endeavour and our dedicated volunteer Board of Directors, we truly understand how much we needed an objective assessment of where we are now and where we are going as an organization. Working with the Endeavour team was an invaluable experience for all of us and has already shaped our thinking. We are truly humbled by the volunteer commitment and have been impressed by the team, the research, and the quality outputs at every stage of the process. Kidney Cancer Canada is very pleased we now have a strong vision and mission that is supported by a sound five year strategic plan we are already executing on!

Thank you Endeavour! Perhaps the very best way to thank Endeavour and all our stakeholders will be to show you in 6 months. . . 1 year. . . 2 years. . . the steps we have made thanks to their efforts over the past 6 months. ONWARD!



Catherine Madden, Executive Director (far left) and Deb Maskens, Chair (far right) with the Endeavour Consulting Team.

Top Ten Tips for Kidney Cancer Survivors

Following diagnosis and initial treatment of kidney cancer, it is important patients have a good understanding of the appropriate long-term surveillance and care required after full or partial kidney removal.

In order to help empower patients, Kidney Cancer Canada has developed the following ten tips for kidney cancer survivors:

- 1 Become Informed** – Learn about kidney cancer and its treatment. Visit the Kidney Cancer Canada website (www.kidneycancerCanada.ca) for up-to-date information.
- 2 Create your own Personal Health Record** – Ask your doctor(s) for a **written** summary of your treatment (including the type of surgery performed and the stage, cell subtype, and grade of your kidney cancer). Share that written summary with all future health care professionals so they are fully informed of your cancer and treatment.
- 3 Be Proactive** – Take charge of your health. Ask questions of your urologist about your follow-up schedule and then keep all appointments.
- 4 Follow a Healthy Lifestyle** – Quit smoking, maintain a healthy weight, monitor your blood pressure and keep it under control, participate in regular physical activity.
- 5 Be Self Aware** – Monitor yourself for any changes in symptoms, both subtle and not so subtle, and report them to your healthcare team.
- 6 Speak Up** – Ask for a referral to cancer support services (such as pain management clinics, social workers, psychological counselling) if you have any physical, emotional or psychological issues related to your cancer.
- 7 Take Care of Your Remaining Kidney(s)** – Drink plenty of water (6-8 glasses per day) and avoid taking medications that are harmful to the kidney (such as ibuprofen, aspirin, NSAIDs).
- 8 Know Your Risk** – Ask your urologist about your risk of possible recurrence of your kidney cancer.
- 9 Schedule Check-Ups** – See your family doctor for an annual physical that includes blood and urine testing, blood pressure monitoring and healthy lifestyle management.
- 10 Remember, You Are Not Alone** – Reach out by calling or connecting online with other survivors at Kidney Cancer Canada (www.kidneycancerCanada.ca).

THANK YOU! *continued from page 2*

Make a tribute gift – recognize a birthday, anniversary, graduation or other special occasion by asking your guests to donate to Kidney Cancer Canada or make a donation to Kidney Cancer Canada yourself in lieu of wedding favours or to recognize a special event for someone else.

Build a legacy – Consider Kidney Cancer Canada in your estate planning through a bequest, endowment, life insurance beneficiary designation, or direction of RRSP/RIF funds.

Organize an event – turn your hobby into an opportunity to raise funds for Kidney Cancer Canada and ask your friends to do the same! Need ideas...

- Hold a golf, card, bowling or dart tournament
- Organize a bike, snowmobile or motorcycle ride
- Invite friends to attend a potluck dinner, coffee party, BBQ or wine tasting event
- Organize a garage sale, yard sale, bake sale or lemonade stand
- Hold a family or neighbourhood walk, run or other exercise-a-thon

What's New in Treatments for RCC?

By Dr. Nina Baluja, Kidney Cancer Canada Director for Ontario

There is always research going on in the area of kidney cancer, with scientists looking for causes of and ways to prevent RCC and improve treatments.

New approaches to local treatment: High-intensity focused ultrasound (HIFU) is a fairly new technique that is now being studied for use in kidney cancer. HIFU involves pointing very focused ultrasound beams from outside the body to destroy the tumour. HIFU is currently being tested in clinical trials in leading cancer centres.

New targeted therapies:

In addition to targeted therapies currently available in Canada (sorafenib (Nexavar), sunitinib (Sutent), temsirolimus (Torisel), everolimus (Afinitor), and pazopanib (Votrient)), two new agents are expected.

New targeted therapies on the immediate horizon include:

- **Axitinib** (brand name Inlyta): axitinib has been shown to inhibit receptor tyrosine kinases including vascular endothelial growth factor receptors (VEGFR)-1, VEGFR-2, and VEGFR-3, all of which are implicated in RCC. On January 27, 2012, the U.S. FDA approved axitinib for the treatment of advanced RCC after failure of one prior systemic therapy. The approval is based on an international, randomized, open-label trial in patients with advanced RCC after failure of one prior systemic regimen. Health Canada review is underway.
- **Tivozanib:** tivozanib is a potent, selective, long half-life inhibitor of all three vascular endothelial growth factor (VEGF) receptors. In January 2012, AVEO and its collaborator Astellas Pharma Inc. announced that tivozanib successfully demonstrated superiority over sorafenib in the primary endpoint of progression-free survival (PFS). Review and possible approval of tivozanib in Canada is awaited.

In addition to finding new medicines and looking at the best way to combine and sequence existing ones, a major area of research lies in finding better ways to select therapy “personalized” for an individual based upon specific tumour characteristics or “biomarkers”.

Upcoming Events

- ▶▶▶ Saturday April 21, 2012 – 9am-4pm (EDT) – TORONTO
Kidney Cancer: Your Journey to Knowledge & Empowerment
Kidney Cancer Canada 3rd Annual Patient Education Conference
Novotel Toronto Centre
45 The Esplanade, Toronto, ON
(Pre-registration required)
 - ▶▶▶ Tuesday May 8, 2012 – 6:30pm-8:30 pm – MANITOBA
Patient & Caregiver Meet & Greet
Kidney cancer patients and caregivers are invited to come and meet other patients and caregivers from Manitoba
Round Table Steakhouse, 800 Pembina HWY, Winnipeg
Dinner is complimentary (One guest per patient only)
(Pre-registration required)
 - ▶▶▶ Thursday June 7, 2012 – 7:00pm-9:30pm (ADT) – NOVA SCOTIA
Hope for Kidney Cancer Patients, Stages I, II, III & IV*
Join us for a patient and caregiver meeting.
Victoria General Hospital, Dickson Building, Room 5110, Halifax, NS
Refreshments at 9 p.m.
Meet fellow patients and caregivers. Friends and family members are welcome.
No charge to attend
(Pre-registration required)
*Also available as a live webcast
 - ▶▶▶ Patient & Caregiver Education and Information Meetings coming soon to a community near you...
 - Montreal, Quebec – September 13, 2012
 - Winnipeg, Manitoba – October 2, 2012
 - Calgary, Alberta – October 24, 2012
 - Vancouver, British Columbia – date TBD
 - Hamilton, Ontario – November 6, 2012
- Check our website for dates and locations at www.kidneycancercanada.ca under “Events”
- How to register:
- 1) Online at www.kidneycancercanada.ca click on “Events” then “Upcoming Meetings”
 - 2) Call 1-866-598-7166



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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

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has adopted the:

