



Kidney
Cancer
Canada

NEWSLETTER

SPRING 2013

Get Moving! The Important Role of Exercise in Survivorship

by Deb Maskens, Chair

You've heard it before, research indicates that exercise improves health outcomes of individuals with many types of cancer. But what about kidney cancer?

The specific role of exercise in kidney cancer incidence is less clear than it is in other cancers, but there is a growing body of evidence to suggest that physical activity may reduce the risk of kidney cancer. For patients already diagnosed, the science unanimously supports benefits for all cancer survivors including:

- Improved sleep
- Improved physical function
- Reduced fatigue
- Improved overall quality of life.

Could a Prescription for Exercise be Effective Medicine?

An evidence review of the international literature demonstrates overwhelming evidence that a physically active lifestyle and formal exercise program can help relieve cancer-related fatigue, muscle weakness, thromboembolism (blood clots), weight gain, loss of bone density, improve quality of life, and reduce psychological distress. In addition, exercise may actually slow the progression of some cancers and reduce the risk of overall death from cancer, as well as reducing the probability of relapse. ⁽¹⁾ Researchers are now investigating the possible biochemical basis for these effects. So yes, in some cancers, exercise has proven equally effective as adjuvant therapy after surgery.

Recent Canadian Research Supports the Need for Intervention

Canadian researchers have recently observed that only about one quarter (25%) of Canadian kidney cancer survivors meet physical activity guidelines ⁽²⁾. Answering a survey mailed to all kidney cancer patients in Alberta, up to 50% of respondents

declared their activity level as completely sedentary (a known risk factor for cardiovascular and other serious diseases). Patients reported that barriers to physical exercise included perceived risk to renal function, perceived increase of the likelihood of recurrence, and social factors including work, family, and other time commitments. (In reality, exercise would likely decrease weight/BMI and improve renal function. Similarly, studies in other cancers (colon, breast) have shown that physical exercise reduces the risk of recurrence.)

Further Research Underway

The good news is that kidney cancer patients expressed interest in participating in an exercise program specifically for kidney cancer survivors. A small clinical trial has started in Alberta to investigate the relationship between quality of life and physical activity in kidney cancer specifically. Patients and researchers alike are interested in how we can best integrate exercise into best survivorship care.

According to Dr. Daniel Santa Mina of The Princess Margaret in Toronto: *"in the absence of exercise evidence that is specific to kidney cancer survivors, lessons and motivation should be gained from the overwhelming body of literature in other oncology*

fields – that is, exercise is a safe and effective way of enhancing physical and psychological strength throughout cancer survivorship."

Patients with kidney cancer should be encouraged, after consultation with their health care providers, to meet established ASCO recommendations for physical activity, which are to achieve at least 150-175 minutes per week of moderate-intensity aerobic activity and avoid inactivity. Do what you love – walk, swim, cycle, play a round of golf or hit the gym. The important message is that we ALL need to get moving more!

For More Information

Before you make any major changes to your exercise program, consult with your physician.

For more information about the relationship between cancer, diet, and exercise, a good resource is the American Institute for Cancer Research:

www.aicr.org

(1) Physical Activity after Cancer: An evidence review of the international literature, Professor Robert Thomas, Mea Holm Bedford Hospital, Bedford, England.

(2) Associations Between Physical Activity and Quality of Life in a Population-Based Sample of Kidney Cancer Survivors, Linda Trinh1, Ronald C. Plotnikoff1,2,5, Ryan E. Rhodes4, Scott North3, and Kerry S. Courneya. Cancer Epidemiol Biomarkers Prev May 2011 20: 859.



My Story

by Robert Kubisch – Winnipeg, MB

My journey began one quiet evening when I was interrupted by an unexpected pain in my groin and right side. It was a colicky pain which soon had me doubled over by the kitchen sink thinking I was going to vomit. I tried to “walk it off” for about 20 minutes, but finally decided to go upstairs and have my wife call 911. But in the moment it took to climb the stairs, the pain completely subsided. I explained to her what had just happened and we were prepared to call 911 should it happen again. I slept through the night without incident and felt well the next morning. It was mid July 2010 and I was 43 years old.

The following day I collected my urine, curious to see if I would catch any stones I may have passed. None were found, but I did collect clumps of blood. After seeing that, I went to the urgent care clinic. Blood work and x-rays were taken but no kidney stones were found. As the CT scanner was not available on the weekend, the doctor asked me to return on Monday for an abdominal CT scan.

On Monday morning I returned thinking all of this was really no big deal. Since the incident on Friday night I had continued to feel normal in every way. I had two CT scans and waited for the results. The doctor called me in and explained that they had found an eight centimetre tumour on my right kidney, which without a doubt, was renal cell carcinoma. My diagnostic files were going to be forwarded to an urologist and the cancer care agency and they would be in touch with me soon.

The day's events seemed surreal to me and I really felt like my days were numbered. My wife had been texting me all day and I stopped responding once I got the news of my tumour. I wanted to share that news in person. By the time I got home, she knew something was terribly wrong; so I finally filled her in. I informed my family and friends and tried to catch up with the gravity of what was happening,

Things moved along very swiftly. Soon I met my urologist, did more tests and prepared for my surgery which was scheduled in three weeks. The doctor decided upon a laproscopic procedure with a radical nephrectomy. I turned to the Internet to research my condition and pending procedure. However, much of the information was pretty gloomy and not always positive. Eventually I stopped researching my illness because it was not emotionally good for me.

The date of the surgery finally arrived and everything went as well as could be expected. The tumour and kidney were removed and there were no signs of metastases. I stayed in the hospital for four days and was glad to return home to recover. No postoperative measures were deemed necessary and I received no chemo or radiation therapy post surgery.



Back at work, news had circulated and a co-worker stopped by to pass on some advice. His dad was an RCC survivor who was doing well and found the Kidney Cancer Canada website to be a valuable resource. I was encouraged by his father's success story and immediately checked out the website. I found it to be the positive, informative and supportive resource I had been looking for.

Two and a half years later I remain under regular surveillance and continue to do well. I feel very fortunate in all of this as everything has played out better than expected. I am grateful to my wife and family for their support, to the doctors and nurses for their professional care, and to all of you walking in the same footsteps You give me the strength and confidence to believe that all of this is going to turn out just fine.

Robert

Cancer: Organized or Chaotic?

A report from our Research Fellow

Dr. Craig Gedye

Are cancers organized or chaotic? One theory is that cancers are like a bee-hive; with many “worker” cancer cells and rare “queen-bee” cancer cells. If this idea is true, then we must identify and target “queen-bee” cells to cure cancers. We call these queen-bees “cancer stem cells”.

The support of Kidney Cancer Canada and the Canadian Institutes of Health Research (CIHR) is allowing me to examine this theory in kidney cancer at the Ontario Cancer Institute working with Dr Laurie Ailles, in collaboration with Dr Michael Jewett and the Uro-Oncology service at University Health Network. My work so far has generated two important discoveries.

To study “cancer stem cells”, we isolate them from patients’ tumours, but separate and remove normal, non-cancer cells (like white blood cells). Intriguingly, we have found that when these normal cells are removed, the kidney cancer cells struggle to grow. This discovery will improve the methods we use to

study cancer stem cells, but also means that we must account for the effect of these normal cells when we study kidney cancer treatments.

Fibroblasts are another group of normal cells that build scaffolds that support tissues and organs. I isolated fibroblasts from kidney cancer but found a mixture of normal and strange looking cells. To understand this mixture we sequenced each tumour’s DNA, looking for each patient’s VHL (von Hippel Lindau) mutation, which we can use as a “fingerprint” to prove whether each cell is a cancer cell or a normal cell. Astoundingly, the group of strange-fibroblast-like cells has exactly the same VHL mutation as clear cell cancer cells in every patient’s cancer we have examined. This means that some of the presumed “normal fibroblasts” are actually cancer cells. This profoundly alters our view of the organization of kidney cancer, and suggests new ideas for treatment and detection.

Thank you for your support!

Kidney Cancer Research Network of Canada

by Joan Basiuk, Director, Medical Relations

Over the course of four days in January, two very important meetings took place just north of Toronto. Many urologists, medical oncologists, scientists, kidney cancer survivors and others were sequestered at the Kingbridge Conference Centre to discuss issues of significance to Canadians with kidney cancer.

The first meeting was "Fostering the Partnership 2: Genitourinary Cancer Survivorship Conference 2013". This meeting was conducted by the Canadian Urological Association and brought together experts, as well as survivors, in the areas of bladder, kidney, prostate and testicular cancer.



The second meeting was the 4th Canadian Kidney Cancer Forum and was conducted by the Kidney Cancer Research Network of Canada (KCRNC).

The presentations and discussions focused on the four main initiatives of the KCRNC: Genetics, Personalized Medicine, Quality of Care and Survivorship.

Lots of exciting ideas and possibilities for future research were generated by the initiative team members. There is

a tremendous amount of work to be done by the KCRNC but the momentum and enthusiasm is definitely there.

As part of the Kidney Cancer Forum, the team from the Canadian Kidney Cancer Information System (CKCis) presented an update on the database project. CKCis is now up and running at 12 sites across Canada and so far, data on approximately 1600 patients has been entered into it. Thank you to all of the patients who have consented to the use of their information.

After several days of hard work, the group participated in the 2nd Hockey Ball Tournament. The four initiative teams, renamed the Genes, Tailors, Qualies and Survivors, played off against each other. The winners of the gold medal were the Survivors!



TAI CHI

by Dale Miron

Total health depends on physical, mental and emotional balance.

Tai Chi is a system of Chinese exercises aimed at creating harmony and total health. The soft flowing and slow turning motions are meant to teach the body and mind to relax. In a relaxed state, you can breathe deeply into the abdominal area bringing more oxygen (Chi) into the body and promoting the flow of blood.

I was amazed at how Tai Chi helped me regain strength, mobility and energy after a radical nephrectomy. Through the gentle, slow turning and stretching motions, areas of tension in the body are relaxed. Each movement has beneficial effects on the digestive, circulatory, muscular, skeletal and respiratory systems. The turning motions massage, strengthen and tone the abdomen. The joints are loosened and the ligaments are exercised. The relaxed rhythmic motions lessen the pressures on the heart. I have been practicing Tai Chi for 8 years and believe it has helped me maintain my blood pressure without medication while first on Sutent and now on Axitinib. Tai Chi has also helped me deal with the extreme fluctuations of emotions that come with being diagnosed with stage 4 metastatic kidney cancer. The slow, rhythmic movements of Tai Chi teach the body to relax while staying present in the moment. The mind is relaxed and at peace. With a relaxed mind we are able to relax the body and internal organs, promoting the flow of energy (Chi). Tai Chi is an excellent complement to my cancer treatment.

Patient & Caregiver Information Meetings – Fall 2012

By Catherine Madden, Executive Director

Kidney Cancer Canada had a very busy fall with several very successful Patient & Caregiver Information Meetings quite literally across this great country.

October saw us in **Vancouver, BC** on the 22nd and **Calgary, Alberta** (with videoconference link to **Edmonton, Alberta**) on the 24th. In Vancouver, attendees heard information regarding “Current Treatments for Kidney Cancer” from Dr. Peter Black, Uro-Oncologist at Vancouver General Hospital. “Gain New Insight into Kidney Cancer” was the theme of the dual-centre video-conference with Dr. Daniel Heng, Dr. Jun Kawakami and Dr. John Robinson, a clinical Psychologist in Calgary and Dr. Ron Moore in Edmonton. Our trip to Western Canada was a great success with over 100 patients, caregivers and healthcare professionals attending the meetings and participating in the lively discussions.

On November 6th we held our Patient & Caregiver Meeting in **Hamilton, Ontario** and we were joined by Dr. Anil Kapoor and Linda Learn, Social Worker discussing “How We Can Treat and You Can Cope with Kidney Cancer Better”. Dr. Kapoor focused on “Management of Kidney Cancer” and Linda Learn shared a very compelling message in her talk titled “Strategies for Coping with a Kidney Cancer Diagnosis”.

Closing out the year, we were in the east coast with meetings in **Newfoundland** on November 28th and **Halifax, Nova Scotia** on December 6th. The meeting in Newfoundland was a “lunch and learn” session with a panel of experts discussing “The Changing Face of Kidney Cancer: Creating Your Survivorship Plan”. Panelists included, Dr. Rorke, Medical Oncologist and Dr. French, Urologist on how they have seen treatment change, Suzy Power, RN (Radiology Department), Bertha Tee on care and compassion issues, Carolyn Jones who addressed social work issues and our Volunteer Director for Newfoundland, Dan Mosher who addressed exercise and cancer. In Halifax, Dr. Ricardo Rendon and Dr. Lori Wood led a Kidney Cancer Canada support meeting for patients and caregivers and discussed topics such as an overview of kidney cancer and “Recent Developments in Kidney Cancer”.

Kidney Cancer Canada is fortunate to have the support of these experts in kidney cancer who share their knowledge and expertise with patients and caregivers across the country so generously. The most compelling and powerful moments in these meetings however belong to the patients and caregivers who share their stories with others. Our special thanks to the following people who inspired everyone by sharing their personal journey with kidney cancer: Robert Schuett in Calgary, Mike Pidberezny in Hamilton and Doris MacKenzie in Halifax.

Be sure to visit our website and watch for our 2013 Patient & Caregiver Meetings happening across Canada. If you can't make the one in your area

you can join online via webcast or watch the videos afterwards.

Videos of the meetings mentioned above (with the exception of Newfoundland) are now available to watch on our website at www.kidneycancercanada.ca or on our YouTube channel at www.youtube.com/KidneyCancerCanada. We hope you will take some time to view the videos and that they will be of help and inspiration to you!



Kidney Cancer Canada Chair, Deb Maskens and Mike Pidberezny, Hamilton.

Upcoming Patient & Caregiver Meetings

►►► **TORONTO** – Thursday, April 4th, 2013

Kidney Cancer 101-Understanding Your Pathology –TORONTO

TIME: 7:00 - 9:00pm Meet and greet, with refreshments, begins at 6:30pm

WHERE: Toronto General Hospital, ELLICSR Centre, BCS021
200 Elizabeth Street, Clinical Services Building

FEATURING: Dr. Andy Evans, MD, PhD, FRCPC
Dr. Craig Gedy, BSc(Hons) MBChB FRACP PhD

(Pre-registration required)

This meeting will also be offered by live webcast

Kidney Cancer Canada is coming to the following centres later in 2013

►►► **OTTAWA, ONTARIO**

►►► **WINNIPEG, MANITOBA**

►►► **LONDON, ONTARIO**

►►► **MONTREAL, QUEBEC**

Watch your email or check out our website for event details as they get confirmed.

Have you visited our new website yet?

Check it out and join our interactive members map
www.kidneycancercanada.ca

Personal Fundraising Pages

There's a new way to support Kidney Cancer Canada. We provide you with all the tools you need to personalize your page, get the word out to your friends and family and ask them for their support. You can build your own Personal Fundraising Page to:

- Support an activity that you are participating in
- Compliment a special event or milestone that you're celebrating
- Create a tribute page In-Honour or In-Memory of a friend or loved one
- Raise funds to support our work

The possibilities are limited only to your imagination! Visit our website at www.kidneycancercanada.ca/support-us/ to learn more or start fundraising now!



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