

LUNG CANCER CONNECTION

WINTER 2015/2016 NEWSLETTER



LUNG
CANCER
CANADA

AWARENESS. SUPPORT. EDUCATION.



GRAEME'S STORY – IN HIS OWN WORDS PART 2

In this issue, we continue with Graeme's Story that we began in our last issue, his is a story of inspiration from a person who is truly living despite having stage IV lung cancer. Graeme was diagnosed in 2010 and is still travelling and leading an active life.

Dr Paul and the Village

It has occurred to me that an oncologist's job must be very difficult. The first time he meets a person, it is to talk about the worst thing that person has heard in their life, so I told him that the way I fight fear is with information and we agreed to be honest, open and not hold things back. The first time I met Paul, we talked for over an hour. I had a lot of questions and he was very good at answering them with clear information and honesty. I apologized for taking so much of his time; I am sure I made him late for many other appointments. He replied "next time I will schedule you for the end of the day so we can talk longer." That is support; that is treating the person.

Dr Paul has always encouraged and supported me in my quality of life decisions. He has written letters to golf courses in Scotland and Ireland so I can rent power golf carts and letters to help me get through security at airports with my Pleurex bottles and supplies. He has successfully sponsored me for two clinical trials and probably pulled a few strings to do it, but most of all I know he believes in me and how I want to go through this journey. He has told me that if he ever gets cancer, he wants it the way I have it.

The same is true of the nurses in the cancer clinic. Very professional and capable but still somehow they have time for a joke and to listen. The first time I went in for a treatment, I started to cry just before the nurse put in the IV. She stopped immediately and asked me what was wrong; I couldn't speak...no words came out... it had just hit me that I was sick, REALLY sick.

Have you tried alternative therapies?

You feel helpless when you have cancer. As an adult, you are used to controlling (or thinking you are controlling) your life. But you can't just put a bandage on it or take two aspirins and call in the morning. Without really understanding the control issue, I did two things... acupuncture and supplements.

My wife's aunt told me about Dr Tran and his clinic. I went for about one year. He did not cure my cancer but the acupuncture did seem to help me keep my energy level up while taking the heavy chemo. Another friend told me about an acquaintance who was surviving stage IV lung cancer and brain cancer for 10 years and still sailing his boat around the Caribbean. I contacted him and got a list of the supplements he was using, researched them and adapted them to what I believed would help me (16 supplements)... mostly anti-inflammatory and immune support.

Did either of these things help me? I know they didn't hurt me and most importantly they made me feel like I was having some control/participation in my well-being. However, before you take any supplements or try alternative therapies, make sure you check with your healthcare team.

The internet. I use information to manage my fears so the internet has been an important tool for me; many patients use it. BUT BEWARE. There are many good and helpful sights but a lot of garbage out there too....mostly emails of miracle cures sent by my well-intentioned friends (lemons).

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PATIENT RESOURCES

A Patient's Guide to Lung Cancer is a Lung Cancer Canada publication designed to meet the educational needs of lung cancer patients and their families.

Available in English and French.

Lung Cancer Canada Info Sheets

Available in English and French.

- Questions to Ask Your Oncologist When You've Been Diagnosed with Lung Cancer
- Lung Cancer and the Use of Oxygen Therapy
- How to Prepare for Lung Cancer Surgery When You Smoke
- Nutrition and Lung Cancer
- For Patients and Caregivers: Coping and Emotional Support
- Thoracic Surgery for Symptom Control
- Managing Daily Activities: Energy Conservation and Work Efficiency

Managing Shortness of Breath

Produced by Lorraine Martelli, MN, RN(EC), Nurse Practitioner Lung DST, Juravinski Cancer Program

The CD consists of a five part series:

1. Introduction/Learning Abdominal Breathing
2. Managing an Acute Episode of Shortness of Breath
3. Sitting to Standing
4. Climbing Stairs
5. Respiratory Muscle Exercises

Check out the video series link on our homepage.

Call or email Lung Cancer Canada to order material

Materials and resources are free for individual patients and caregivers.

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**LUNG
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2015 FACES OF LUNG CANCER REPORT

Lung Cancer Canada's **Faces of Lung Cancer: One Patient, One Diagnosis, Countless Casualties**, is an in-depth look at lung cancer in Canada and uses the results of the 2015 patient and caregiver survey to give voice to the human toll of this disease. Providing new

perspectives on the country's deadliest cancer, the report speaks to a virtual avalanche that devastates and impacts countless lives and systems in its path. In a disease with low survival rates, we are at risk of failing patients and caregivers due to obstacles to accessing life-prolonging treatment, limited research investment and inadequate availability of local support services, as well as a concerning lack of compassion for patients and caregivers living with the disease.

The inequities start even before diagnosis. Depending on where a patient lives, it can impact how quickly they are diagnosed, the support they can access, and how long it will take to see a specialist and receive treatment.

Caregivers are key soldiers in a patient's fight but this comes at a high cost. 59% of caregivers reduce the number of hours they work, and a further 8% quit their jobs to look after a loved one with lung cancer. 50% of caregivers reported a negative impact on their household finances.



2015 Faces of Lung Cancer Report

When asked what would make caregiving easier to manage, caregivers most often mention greater empathy towards lung cancer in general and better access to support services. However the survey showed that only 26% of caregivers have ever received these services. Even when they are offered, wait times and access points can differ between provinces, regions, and cities.

The deep-seated perception that lung cancer is self-inflicted places an additional burden on families. This negative stigma prevails despite the fact that the majority of Canadian lung cancer patients are ex-smokers, and many never smoked at all.

Although lung cancer has the highest mortality of all cancers in Canada, it receives a disproportionate amount of research investment compared with both the scope of the cancer and with other cancers. In fact, as of 2012, significantly more funds were going into research for breast cancer and prostate cancer. While it is important that research continue in these cancers, it is also important to acknowledge the obvious need for more investment in lung cancer research that, at the very least, matches the significant burden of disease. Indeed lung cancer kills more Canadians per year than breast, prostate and colorectal cancers combined.

As outlined in the report, lung cancer patients and their caregivers continue to face a number of significant challenges. This needs to change. Lung Cancer Canada urges all Canadians to step-up and advocate for everyone who suffers from lung cancer. 🌱

Clinical Trials – An Underused Standard of Care

One of the focal areas of the **Faces of Lung Cancer Report** centred on participation in clinical trials. There were several factors found that were likely to influence patient participation. Patients whose cancer has spread at diagnosis were more likely to enrol in clinical trials than those with localized lung cancer (37% vs. 15%). This is likely because there are more clinical trials available for patients with metastatic disease.

Participation in clinical trials was also found to be positively correlated with household income. Patients with a household income of over \$100,000 per year were almost twice as likely to participate in clinical trials. Given that low socioeconomic

status has been linked to lung cancer, greater effort is required to ensure that everyone has equal access to new, cutting edge therapies through clinical trials.

Lung Cancer Canada believes that access to clinical trials should be a part of the standard of care and that all patients should be offered a clinical trial as an option, where available. Lung Cancer Canada recommends examining trial reimbursement and rollout strategies to allow smaller centres to participate. Patient's access to clinical trials must be facilitated, especially in cases when travel and time off work take a significant financial toll. 🌱

Clinical Trials - Questions to Ask:

Why participate in a clinical trial?

When you are in a clinical trial, you gain access to new research treatments before they are widely available and help others by contributing to medical research.

Who can participate in a clinical trial?

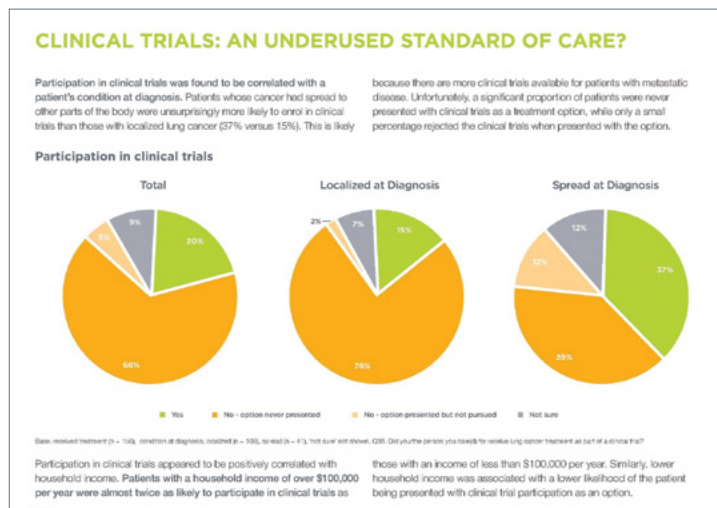
All clinical trials have guidelines and criteria about who can participate. These criteria are based on factors such as age, sex, the type and stage of a disease, previous treatment history and other medical conditions. It is important to note that these criteria are not used to reject people personally. Instead, the criteria are used to identify appropriate participants and keep them safe. The criteria help ensure that researchers will be able to answer the questions they plan to study.

What should you consider before participating in a trial?

You should know as much as possible about the clinical trial and feel comfortable asking the members of the healthcare

team questions about it, the care expected while in a trial and the cost of the trial. 🌱

For a list of ongoing clinical trials in lung cancer, visit lungcancercanada.ca/Lung-Cancer/Clinical-Trials.aspx



Participation in clinical trials was found to be correlated with a patient's condition at diagnosis.

COMMUNITY ACTION FOR HOPE

Voices of Lung Cancer

Community involvement not only matters, but is key in the fight to raise awareness of the topical issues surrounding lung cancer. Whether it is an annual event, a fundraiser or a one off meeting with like-minded individuals, every little bit helps. Bringing people together with one cause, one vision and one voice, communities make the difference!

On September 30, 2015 Lung Cancer Canada hosted a **reception at Queen's Park**, sponsored by Kathryn McGarry, the Liberal MPP for Cambridge and included speakers Jeff Yurek, Conservative Health Critic and MPP for Elgin-Middlesex-London; John Fraser, Liberal MPP for Ottawa South and Parliamentary Assistant to the Minister of Health and Long-Term Care; France Gélinas, NDP Health Critic and MPP for Nickel Belt; Tim Hudak, PC MPP for Niagara West-Glanbrook and other invited guests. This was a chance for constituents to meet with their Ontario MPP's to have their voices heard, "we

are the members of your community and we want to discuss the important issues surrounding lung cancer!" Roz Brodsky, a local constituent of the Thornhill riding and LCC board member, was able to speak with her MPP, Gila Martow.

We would like to thank those who participated, especially all of the MPP's who took the time to meet with us for a productive and enlightening day. 🌱



Kathryn McGarry, the Liberal MPP for Cambridge

Aaron Howson Fundraiser – Locks for Lung Cancer!

Aaron Howson brought his community together by growing out his hair and starting a fundraiser in his mother's name. "I initially started growing my hair 2 1/2 years ago. Last July, this fundraiser became a little more personal when my mother, Denise, was diagnosed with adenocarcinoma. I put it out on Facebook that it was HAIRCUT TIME! I asked for donations in my mom's name, with an intended donation of \$2000.

Within 12 hours, I had reached that goal, and the donations kept coming! Thank you just didn't seem like enough when we received their donations.

In total we forwarded more than \$7500 to Lung Cancer Canada for them to continue to provide awareness, advocacy, education, and research initiatives for patients and families affected by lung cancer."
-Aaron Howson



Aaron Howson (with wife Jen), before and after

Excellent job Aaron, we thank you and your former locks! 🍀

Donnie Mac Hockey Tournament

The **Donnie Mac Cup** is a memorial hockey tournament that brings together the community in St. Albert, Alberta, annually. This year's 3rd Annual Donnie Mac Cup took place on Saturday, April 11th, and raised almost \$6000 for the fight against lung cancer!



Thank you to the **Donny Mac Cup!**

The Donnie Mac Cup is played in honour of Don MacMillan, a St. Albert Resident, who passed away of lung cancer on March 19, 2011 at age 61. 🍀

"The hope I was trying to portray was right in front of me. I went from crying every night in the shower so my boys would not hear me, to 'it's going to be okay'. Hope went from just something I said to becoming real. My older child is 13. I'm determined to meet my grandchildren."

- Lung Cancer Patient

Pedal Towards the Cure

MacKenzie Lucas lost both of his grandparents to cancer; as a result he decided that he was going to ride his bike across Canada in order to raise money for lung cancer.



MacKenzie Lucas has inspired us all!

Unfortunately, due to developing tendonitis in his knee, he had to cut the ride short. That hasn't stopped him from hoping to one day pick up where he left off in Riviere du loup, Quebec and finish his dream of riding across the nation.

It just goes to show that despite obstacles and setbacks, where there is determination, there is hope! "It was an amazing journey, I saw some amazing things, and met some amazing people." Lung Cancer Canada would like to thank MacKenzie for the inspiring ride, we were cheering for you all the way! 🍀

Convoy for Hope – Atlantic

The **Convoy for Hope - Atlantic**, brings together Atlantic Canadians to celebrate the great service of the trucking industry and to support our communities in the fight against cancer. This year's event raised awareness and funds to combat breast cancer, lung cancer, prostate cancer and colon cancer.



The **Convoy for Hope** has been donating to lung cancer for the past several years.

The Convoy was a huge success with fantastic weather and a great turn out including 23 registered transport trucks, three fire trucks, 14 CAV Motorcycle crew and 24 volunteers! Thanks to all for your participation, attendance and support; \$7000 was raised for lung cancer. 🍀

Scotiabank Toronto Waterfront Marathon

On October 18, 2015 Lung Cancer Canada participated in the **Scotiabank Toronto Waterfront Marathon**. There were over 180 official charities in the Charity Challenge, and we were happy to be a part of such a wonderful group! A total of \$23,801 was raised for lung cancer awareness!

Lung Cancer Canada is a small organization but it is our friends and supporters, like you, who make us stronger and have increased our profile. Because of you, Lung Cancer Canada is able to participate in meaningful events such as these. With your help we are able to raise awareness for the issues facing lung cancer patients as well as much needed funds in our fight against lung cancer. Lung Cancer Canada would like to thank all of our supporters – runners, walkers, volunteers and pledge seekers. Despite an early morning, very cold temperatures and gusty winds, there were a lot of warm

faces and positive spirit, all for a great cause and we very much appreciate it.

A special thank you goes out to **Judy Cole** who has participated in and gathered support for multiple runs for Lung Cancer Canada.

“Running has been part of my life for almost 40

years. After my diagnosis of bronchioloalveolar carcinoma and subsequent right lobectomy in 2008, I worked my way back to running 5 km. Since then, I have participated in the Scotiabank Toronto Waterfront Marathon 5 km event, raising funds for Lung Cancer Canada. Each time I run, I celebrate my own recovery, and hope that my efforts will help researchers with theirs.” – Judy Cole 🌿



Thank you to **Judy Cole** (far right) and all of our runners

AN EVENING OF HOPE

An Evening of Hope - Toronto

On November 12, 2015 Lung Cancer Canada held its annual **Evening of Hope**. This annual event brings together the different circles of the lung cancer communities. It is a chance to recognize and show appreciation for the patients, families, our partners and especially the healthcare providers and professionals whose daily mission is to improve survivability for this disease. Above all it is a celebration of hope! We would like to thank all of our speakers, presenters, supporters and volunteers for helping to make the Evening of Hope a tremendous success! Attendees had the opportunity to meet, share stories and take part in our auctions. Some moving speeches were given by **Anne-Marie Cerato** (a lung cancer patient who just got married), **Christina Amaral** (who just lost her father to lung cancer), and **Joseph Neale** (a young singer who lost a lung to lung cancer). Joseph finished the night off with a powerful vocal performance. 🌿



An Evening of Hope –
Toronto 2015

Casey Cosgrove (left) and **Diane Zawisza** (RN), Clinical trials nurse at Princess Margaret (right)



HOPE IN OTTAWA

Evening of Hope - Ottawa

Ottawa has its own Evening of Hope on November 19, 2015. Elizabeth Dessureault, a young and vibrant 26-year old, who was diagnosed with lung cancer while pregnant, had a chance to speak at the Evening of Hope. "I want to help change the face of lung cancer," she said. "There is a stigma that it is only a smokers' disease. That is not the case, young lung cancer is on the rise, and we need funding for research to figure out why this is happening." Elizabeth is raising hope in her community as well. She generates awareness on her blog *From Lizzie's Lungs* and has raised funds through her Lung Cancer Awareness bracelets and many other endeavours.



Elizabeth Dessureault (right)

Funds raised from both Evenings will be used to increase public awareness of lung cancer, advocate for lung cancer patients and their families, provide educational and peer resources, and support promising research opportunities. Thank you to all who attended the Evening of Hope and gave so generously! 🌱

Philip Clarke Golf Classic

When a small group of Old Ottawa South residents decided to organize a charity golf tournament to remember their good friend Philip Clarke (who died of lung cancer in 2013), their aspirations were modest. Perhaps they could interest 70 or so people in attending, and raise around \$5000 for Lung Cancer Canada. Well on September 17 they realized those goals, and then some.

A gross of golfers (yes that's 144) filled Falcon Ridge golf course for a round of sun-drenched golf. In the end \$23,000 was raised for lung cancer research, education and awareness. That was the first annual "**Philip Clarke Golf Classic – A Tournament of Hope**". Expect it to be an ongoing feature of the OOS calendar. 🌱

Curling to Kick Cancer

Just over four years ago, Mark Deschamps, a very healthy, non-smoking, 40 year-old husband, father, son, brother, and friend was diagnosed with Stage IV Lung Cancer. The annual **Curling to Kick Cancer** event started shortly after in an effort to bring together a community that supported him, promote awareness, lift stigmas, and raise funds for Lung Cancer Canada. The event is geared towards those who don't curl, where funny team uniforms are encouraged and great live music throughout the day! They have doubled in size every year and as a result have added a second event for 2016.



Bowling to Strike Out Cancer is scheduled for April 23, 2016. Curling to Kick Cancer 2016 will happen in October. 🌱

Order of Canada

Lung Cancer Canada is proud to announce that **Dr Frances Shepherd**, Honorary Board Member of LCC, has been appointed **Officer of the Order of Canada** for her leadership in improving treatment options and outcomes for



Dr Frances Shepherd

individuals with advanced lung cancer. Dr Shepherd has always been a tremendous supporter of LCC's efforts, and was the Keynote Speaker at LCC's inaugural Evening of Hope in 2011. More importantly, her research has had global impact in advancing lung cancer care and improving survival rates in this disease. She initiated studies that led to life-prolonging treatments in advanced cancer and to increasing the cure rate of lung cancer surgery through preventive chemotherapy. 🌱



SELFIES OF HOPE, VOICES FOR LUNG CANCER



Selfies of hope, voices for lung cancer awareness.

My Wish for Lung Cancer Awareness. As part of our **Queen's Park event** and our **Evening of Hope** in Toronto, we encouraged attendees to take selfies, alone or in a group, expressing a wish: a message of hope and inspiration

for lung cancer awareness. We encourage YOU to do the same! Send us your selfie with your "I wish for..." message of hope by email, Facebook or Twitter. Use the hashtag **#SHOVElungcancer** and we will share it for all to see! 🌱

GRAEME'S STORY

CONTINUED FROM PAGE 1

What do you worry about most?

My wife. Cancer is harder on the survivors than the victim. Yes my fantastic journey will end so that makes my job easy... live as long as I can, but she has to come on this journey with me and face another journey without me. No one, not even Dr Paul, can truly understand how it feels to have cancer and this makes it very hard on the ones who love you the most. The ones who would do anything to make it better.

I don't know how to make things easier for Carole. Cancer is with us every day, spoken or not. I can focus on myself, she has to focus on everything else and while I do as much as I can, a lot of the things in daily living fall on her.

I have had time to arrange my affairs to make it as easy as possible for her to be alone (bills, websites and passwords, investments) but I do not know how to help her and the rest of my family deal with the grief that my passing will bring.

I have always said that I am very lucky to have this long a journey, to have been able to write this epic novel. Without being overly dramatic about recent events, I have always likened my journey to death to that of a soldier who gets up one day and is dead that afternoon; I have been given the time to say goodbye, to deepen my love with my wife, to make new memories, to spend quality time with family and friends, to reconnect with high school buddies and work colleagues, to share memories of our lives. 🌱



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