



LUNG CANCER CANADA

Awareness. Support. Education.



Edition Fall 2012

Lung Cancer Canada Working For You

Natasha Leighl, President of the Board

“What do Canadian lung cancer patients and their caregivers most need from Lung Cancer Canada over the next few years, and how do we focus the organization on those needs?”



In August, the Lung Cancer Canada (LCC) Board of Directors convened a strategy session to answer this question. Our objective was to improve the quality of our support and education for people with lung cancer, as well as promote greater

awareness, compassion and research funding for lung cancer. Directors, staff, volunteers, members of our medical network and colleagues from other cancer support organizations came from across Canada to discuss how to better meet the needs of Canadians living with lung cancer.

We identified four key areas on which to focus over the next two years, including Patient and Caregiver Matters, Advocacy for Lung Cancer, Screening for Lung Cancer and Developing a National Vision for the organization. In order to achieve greater strength in these four areas, we recognized that we must enhance our ability to raise funds and realign our current structure to better focus on and serve the needs of patients and caregivers.

Under the leadership of LCC Board Director Ms. Lorraine Martelli-Reid, the LCC Program Committee will ensure our existing programs and supports are aligned with the needs of patients and caregivers. In addition, we will increase the reach of our services by implementing an outreach strategy—including the development of an online platform—to broaden our community and support people with lung cancer nationally.

Advocacy continues to be a challenge in lung cancer. LCC will revitalize its advocacy efforts with an initial focus on lung cancer

screening. Most Canadians are unaware that there is now effective screening for lung cancer with low-dose computed tomography (CT) scans. Early detection of lung cancer through screening will save more lives than mammography for breast cancer or screening for prostate cancer! LCC is advocating for a national screening program for those at risk across Canada. This will help change the face of this disease and dramatically increase the survival of those diagnosed with lung cancer.

Over the next two years, the board of directors will restructure LCC to develop a national vision and national accountability for the organization. To accomplish our goals in the four key areas of focus, we need more help. LCC will further develop its media and public relations expertise, especially surrounding lung cancer advocacy. We will increase our fundraising capacity in order to better support programs and resources for people with lung cancer. And we will expand our pool of staff and recruit more volunteers nationally to support our mission of meeting the needs of Canadian lung cancer patients and their caregivers.

Please join us in our quest to build more hope and a brighter future for all those fighting against lung cancer.



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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-Reid, 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

Call or email Lung Cancer Canada to order material.

Material and resources are free for individual patients and caregivers.



Relaxation Techniques

Check out the video series link on our homepage

Contact Information

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Toronto, Ontario M4Y 1P9

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Email: info@lungcancercanada.ca

Connect with us    from our homepage:

www.lungcancercanada.ca

Charitable Registration Number: 872775119 RR0001

We've moved!

Lung Cancer Canada wishes to acknowledge our community partners:





Getting a Lung Cancer Diagnosis at Age 30

Anne Marie Cerato

I have a long history with lung cancer. Before I was born, my grandmother had the disease, and when I was a child, my grandfather had half his lung removed. In my twenties, my father was diagnosed with terminal mesothelioma, and finally, at age 30, it was me.

My own journey with this disease began in 2009. I noticed a small node on my clavicle which motivated me to get to my doctor. One x-ray, CT scan and biopsy later I was diagnosed with lung cancer. What happened next was a blur of tests, appointments and consultations. My family doctor moved mountains and subsequently saved my life!

It was determined that I had stage 3A adenocarcinoma. I was told that the best and most aggressive course of action would be to have concurrent radiation and chemotherapy, then surgery followed by more chemo. The next six months involved daily or weekly trips to Sunnybrook, until I received my last dose of chemo on Dec 24—a Merry Christmas indeed! During treatment, I felt supported by my medical team, they answered my questions and addressed my concerns. But that ended abruptly when treatment ended, and I felt isolated and alone even though I had an incredible support system in my friends and family.

Every three months, I returned to the hospital for my scheduled barrage of tests. This continued for one year until May of 2011 when it was determined that my cancer had returned. This time, nodules were present in both lungs and in multiple lobes. Radiation and surgery were not an option, and chemotherapy wasn't recommended because I was asymptomatic and it would just make me feel sick. I was to wait until symptoms began to show. I continued active monitoring—which felt more like passive dying—until I read about a promising targeted therapy called Crizotinib. I immediately emailed my nurse and bombarded her with questions. What is this drug? Is the trial in Canada? How do I get on the trial? I was referred to Lakeridge hospital where they were conducting trials.

Testing of my tumour revealed that I have the EML4-ALK mutation. Luckily I was randomized to the group that got the study drug. Since September 2011, I have taken 250mg of Crizotinib twice per day and although I have and continue to experience side effects, I have hope for a long life. Each scan since my first has shown improvement to the point that my lungs look normal! A little over a year ago, I was striving to hit 40, now I'm looking way into my future. My condition, although incurable, is now manageable and chronic, not terminal!

Even living in a world-class city like Toronto, I have found it incredibly difficult to find resources and outlets for young

adults living with cancer. Young adults with cancer have unique and different needs than older adults. A 65 year old might be worried that they can't vacation because of treatment; a 30 year old is worried about loss of independence, fertility, career change and other psychosocial and financial challenges due to treatment.

The face of lung cancer is changing. More and more, that face looks a lot like mine— young, non-smoker, asymptomatic and healthy (well, except for the cancer). Gone are the days that we can associate lung cancer only to smokers or those who have been exposed to 2nd hand smoke, because it is an injustice to those like me who are neither. I want people to know that the stigma of lung cancer is killing us. No one deserves cancer, whether they smoked or not.

It amazes me that even with the abysmal amount of funding given to lung cancer research and patient support, that those involved in our treatment and care are able to make such strides. The advent of genetic testing and new targeted treatments has given people like me so much hope. I am so grateful that Lung Cancer Canada exists to advocate on our behalf and for the dedication and tenacity of the professionals and patients who continue to push for more dollars and better treatments. I can only imagine what they could do if we had adequate funding.

Roberta Winton, Anne Marie Cerato (middle), and Patrick Bardos at the LCC Evening of Hope gala





Modern Day Chest Surgery—*Less Pain for the Same Gain* *A Quick Look at Minimally Invasive Chest Surgery*

Chuck Wen MD, MSc, BSc, Colin Schieman MD, BSc, FRCSC

Division of Thoracic Surgery, McMaster University, Hamilton

Video-assisted thoracic surgery (VATS) is a surgical technique used by thoracic surgeons to perform operations inside the chest. This technique is minimally invasive since it is a form of “key-hole” surgery, where operations are performed using incisions that are much smaller than those created in traditional surgery. Since its introduction in the 1980’s, the VATS technique has quickly grown in popularity due to growing awareness of its potential advantages for patients: less post-operative pain, shorter hospital stays after surgery, faster recovery times, better immune response, improved breathing and fewer respiratory complications.

Similar to traditional chest surgeries, VATS procedures are performed in the operating room where the patient is given a general anesthetic. Multiple small incisions (2–4cm) are typically made between the patient’s ribs, these incisions are smaller than the 10–15cm incisions typically used in traditional surgeries. Long slender instruments (VATS instruments) are then inserted through these small incisions to perform the operation. One such instrument is a special video camera known as a thoracoscope, which provides the surgeon a magnified view within the chest cavity. This enables the surgeon to handle the tissues and organs inside the chest with great precision and without the need for the larger traditional incision. In addition, with VATS the stress caused by the spreading of ribs is avoided. Such rib spreading is necessary with traditional “open” surgeries, and it is believed to contribute significantly to the patient’s post-operative pain.

Patients undergoing VATS procedures do not need to do any extra preparation than what is typically required for traditional surgeries. In some cases, surgeons may begin using a VATS approach but may need to switch to a traditional approach with a larger incision. The surgeon may make this decision during the operation should greater access into the chest cavity be required to complete the surgery in the safest manner possible.

In recent years, a wide variety of surgeries have been performed using VATS. These include biopsies of the lung and lymph nodes, removal of lung segments or lobes for the treatment of lung cancer, as well as the drainage and treatment of fluid that may have accumulated within the chest cavity (i.e., pleural effusions) due to various diseases. Given its many applications, VATS has proven to be a versatile and highly useful method.

It is important to note that the VATS approach may not be suitable for every patient or instance where the surgeon may need greater access to the problem area in the chest. Tumour size and location, as well as history of prior chemotherapy, radiation therapy and/or chest surgery, all help to determine whether VATS is a good option for the patient. Therefore, it is important for the surgeon and patient to review options in advance to determine if VATS is the best approach in meeting the patient’s needs.

We did it together!

The Scotia Waterfront Charity Challenge



Lung Cancer Canada was chosen to be one of three featured charities for this year’s Scotiabank Toronto Waterfront Marathon. With the help of our dedicated volunteers, we participated in the two-day expo at the Direct Energy Centre, distributing over 5,000 information brochures and tote bags and answering questions to help raise awareness about this devastating disease.

We are most grateful to the 75 runners, walkers and marathoners that joined us in October, and to the 800+ donors that helped us to raise \$70,000 this year—our most successful year ever! This is a victory for Lung Cancer Canada, but most importantly for those living with lung cancer.

On behalf of the board of directors and staff at Lung Cancer Canada, thank you for your outstanding contribution.



Lung Cancer Awareness Month

This past year, Lung Cancer Canada embarked upon a national awareness campaign to raise the profile and understanding of lung cancer in our country. We believe it's time to leave the stigma of tobacco behind and build the necessary supports that people with lung cancer and their families need and deserve. We envision a country that unites to help bring an end to lung cancer, and with that we strive to promote greater investment in research for a cure.



Photos courtesy of T.H. Jackson Huang, IKonica

LUNG CANCER CANADA'S EVENING OF HOPE

More than 200 people gathered at our second annual Evening of Hope gala, a celebration of survivorship and the considerable scientific progress being made in the fight against this devastating disease.

Our keynote speaker, Ms. Anne Marie Cerato, shared her personal experience and shock of receiving a lung cancer diagnosis at the age of thirty. Now thirty-four, Anne Marie is a young, vibrant woman living with lung cancer. Another highlight and milestone for Lung Cancer Canada was the launch of the Gabriella Micallef Young Investigators Award. Ms. Kalia Douglas-Micallef and Chris Fenn delivered a heart-felt speech in memory of Gabriella and the launch of our first ever research grant for young investigators. And finally, founder and long-time honorary board member, Mr. Ralph Gouda, shared his deep appreciation to those that have kept the memory of Nadia Gouda alive by working tirelessly toward the mission of Lung Cancer Canada.

On behalf of the board of directors, staff and those living with lung cancer, we'd like to pay special thanks to everyone that helped make this evening a tremendous success. Our second annual Evening of Hope was dedicated to celebrating advances in lung cancer, raising awareness and raising money for our research fund.

The LCC gala raised an amazing \$70,000 for our research fund. Thank you to the following supporters that helped to make our Evening of Hope a great success

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Our special thanks go to our prize sponsors, as well as Melissa Haggerty and Gabi Slaninova of Spectacular Spectacular. Their expertise was instrumental in creating a wonderful atmosphere complete with culinary delights, music, décor and our very own Tree of Hope. The most exciting part was watching guests competing for the grand prize of a 14-carat white-gold diamond pendant necklace by Design Fine Jewellery Ltd., donated by Roz & Howard Brodsky.



SPECIAL REPORT

1 in 6 Canadians think they are more likely to dance on stage with Justin Bieber than get lung cancer in their lifetime. Public knowledge about lung cancer and its impact is all too scarce. Read more results from our national poll at: www.lungcancercanada.ca

NEW

Lung Cancer Canada's Lung Nurses Network

In the spring of 2012, nurses from across Canada were surveyed to ascertain interest in developing a Lung Nurses Network as a division of Lung Cancer Canada. Fifty nurses from almost every province have since joined the network and 5 nurses—Lorraine Martelli-Reid, Lynne Penton, Suzy Power, Linda Gandy, Karen Levy and Carolyn McFadden—have formed a steering committee to guide development of the vision and objectives.

“Our vision is to support, educate and promote collaboration among nurses working with patients and families affected by lung cancer,” says Lorraine Martelli-Reid, Nurse Practitioner at the Juravinski Cancer Centre. “Through increased knowledge, sharing and leading practice change, we can ensure access to a uniformly high quality of care across Canada to achieve the best possible outcomes for patients and families affected by lung cancer.”

The objectives developed by the steering committee include creating a network of oncology nurses across Canada who work with patients and families affected by lung cancer, promoting evidence-informed nursing best practices and patient-centred care, and facilitating access to/creating educational resources that promote professional and clinical growth to improve outcomes in patients.

If you are a nurse or student nurse interested in lung cancer, click on the Lung Nurses Network logo found on LCC's homepage. You will be led to our webpage which will continue to grow and provide resources and learning modules to help you care for those affected by lung cancer. To join the network, email: lorraine.martelli-reid@jcc.hhsc.ca to express your interest.



The human hand in the logo of the Lung Nurses Network represents outreach, skill and caring, while the apple blossom leaves represent lungs and symbolize health, hope and renewal.

The Gabriella Micallef Memorial Hope Research Grant

During our Evening of Hope on November 1, 2012, Kalia Douglas-Micallef, 15 year old daughter of the late Gabriella (Gabey) Micallef, and her cousin Mr. Chris Fenn gave a heartfelt speech announcing The Gabriella Micallef Memorial Hope Research Grant.

“Lung cancer kills more Canadians each year than breast cancer, prostate cancer and colon cancer combined,” Chris announced, “yet it receives minimal public and government support and little research funding. With this research grant, Gabey’s hopefulness lives on, and as we celebrate a life well lived, we remain as hopeful as she was that one day cancer will be beaten and the statistics will wither.”

Kalia and Chris thanked family, friends and businesses who were inspired by Gabey’s legacy.

Gabey raised over \$50,000 to establish a unique research grant aimed at promoting a greater understanding of behaviours and/or common attributes of long-term survivors of lung cancer, including use of potential integrative or supportive therapies to improve patient outcomes.



“My mom was very strong, and she believed that she could survive cancer. I believe that she did. Sometimes winning isn’t living forever, but living well and longer than anyone ever thought you would.”

For more information or to apply for this grant, visit www.lungcancerCanada.ca