



LUNG CANCER CANADA

Awareness. Support. Education.



Spring 2013 Edition

## Lung Cancer in Canada: An Overview of LCC's First-Ever Public Opinion Poll

There is no question that the lung cancer fight is suffering from a general lack of public awareness and understanding of the disease. In order to elevate the lung cancer conversation in this country, Lung Cancer Canada conducted benchmark research on Canadians' knowledge of and attitudes toward lung cancer. Our hope: to begin the critical process of clearing away misconceptions and educating the general public about this devastating disease.

Our groundbreaking poll by Pollara revealed that while lung cancer hits close to home for the majority of Canadians—over half (51%) know a family member, friend, co-worker or neighbour who has or had lung cancer—public knowledge about the disease and its impact is all too scarce.

Although 1 in 12 Canadians will be diagnosed with lung cancer, nearly half (47%) of those surveyed estimated that no more than 1 in 50 Canadians will be diagnosed with lung cancer in their lifetime, and an additional 32% had no idea of the odds. Indeed, more than 1 in 6 Canadians think they are more likely to dance on stage with Justin Bieber than get lung cancer in their lifetime.

The poll also evidenced scant awareness of just how deadly the disease is. When asked about the five-year survival rate for lung cancer—which has hovered around 15% for decades—91% of Canadians either had no idea what it was or had an inflated view of the disease's five-year survival rate (overestimating on average by almost 300%).

### Concern and Understanding of Risk are Lacking

While lung cancer will kill more than 20,000 Canadians this year, most Canadians do not take their lung cancer risk seriously. Over half of those surveyed (54%), including two-thirds of never smokers, say that they are not concerned about getting lung cancer or have never really thought about it. Nearly nine in ten Canadians (89%) have never talked to their doctor about their risk for lung cancer, and only 1% know radon gas (a naturally occurring gas found in confined areas such as attics, basements, spring waters or hot springs) is the second most common cause of lung cancer.

### Women and Lung Cancer

Unfortunately, one area where Canadian women are catching up to men is in lung cancer diagnoses. Lung cancer will kill nearly 10,000 women this year—at least 80% more than the number of

women who died from breast cancer in 2012 and more than the total number of deaths among women from breast, uterine and ovarian cancers combined. Yet, only 11% of women correctly identified lung cancer as the top cancer killer of women (58% thought breast cancer was the top killer, followed by 13% who cited gynecological cancers).

### Have Sympathy and Support Gone Up In Smoke?

The survey found that one of the reasons the Canadian public has largely turned a blind eye to the disease is its association with smoking. Despite the fact that 80% of Canadians believe nicotine is addictive and 68% believe that smoking is a disease like alcoholism, when it comes to lung cancer, a "blame the victim" mentality is common. Nearly two-thirds (65%) of those surveyed said that smokers are "very responsible" for what happens to them as a result of their smoking habit—less sympathy than is evidenced in the survey for gamblers, drug addicts, heavy drinkers or unhealthy eaters.

*"The fact that most Canadians are unconcerned about a disease that accounts for over a quarter of all cancer deaths in this country only reinforces how much work we have to do," said Dr. Natasha Leighl, President of Lung Cancer Canada and a medical oncologist at Princess Margaret Hospital in Toronto. "Ignoring this dreadful disease won't make it go away."*



SPECIAL REPORT

Read more results from our national poll at: [www.lungcancerCanada.ca](http://www.lungcancerCanada.ca)

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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 six 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



### **6. Relaxation Techniques**

Check out the video series link on our homepage

**Call or email Lung Cancer Canada to order material.**

Material and resources are free for individual patients and caregivers.

## *Contact Information*

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**[www.lungcancerCanada.ca](http://www.lungcancerCanada.ca)**

Charitable Registration Number: 872775119 RR0001

**We've moved!**

Lung Cancer Canada wishes to acknowledge our community partners:





# Faith, Support and Care are as Important as the Cure

**Thi Do**



I was diagnosed with stage 4 lung cancer in 2008 at the age of 46. I had always led a healthy lifestyle and did not smoke. The news was surprising and devastating; my family and friends were in shock. I felt hopeless. I am a very religious Catholic—during the critical times I prayed almost constantly.

I was treated with radiation followed by chemotherapy at the Odette Cancer Centre at Sunnybrook Hospital. Too weak to tolerate more than four chemo sessions, my doctor suggested I take Tarceva, at that time a new cancer drug reported to work very well on non-smoking Asian women with lung cancer. Within a month I started to feel better and this continued for nearly three years.

In August 2011, I started to feel more fatigued, I lost weight and had no appetite. A CT scan showed the tumour was bigger—the Tarceva was no longer working. I was scared of more chemotherapy, but I was told that this chemo was different than the one I had four years ago and that the side effects would be milder.

With the encouragement of my family, and with the help from the medical staff at the Odette Cancer Centre, I was able to fight the cancer. I was well cared for, and I received assistance to apply for drug cost reimbursements from Roche Laboratories and the Trillium Drug Program. The social worker even helped me to apply for a visitor's visa so my sisters could come from Vietnam to be with me.

My belief is that with a strong will and religious faith, good support from the ones close to you and with the care of a caring medical team, we can fight back against lung cancer.

## Greater Awareness, Hope and Dollars are Critical

Raising lung cancer's low public profile is critical to progress. Unfortunately, the disease has yet to capture the public's attention. As the only national organization in Canada focused exclusively on lung cancer education, advocacy and patient support, it's our mission to inform the Canadian public on this devastating, relentless killer and increase Canadians' determination and capacity to fight back.

We can't do it without you!! Thank you to the following supporters for your tireless efforts to raise money and awareness for Lung Cancer Canada.

### CONVOY FOR HOPE "DRIVING OUT CANCER ONE TRUCK AT A TIME!"

*Jo-Anne Phillips, Event organizer*

The 2012 Convoy for Hope—Atlantic was a huge success! We were thrilled with the turnout and the support for the rebirth of this important event to help raise funds and awareness for lung cancer. The spectators lined the overpasses waving their flags and banners, and participants were celebrated and awarded for their hard work. We were honoured to have the survivors there to share their stories.

In partnership with the Beatrice Hunter Cancer Research Institute in Atlantic Canada, a portion of the funds raised in 2012 has been used to support a Lung Cancer Canada trainee award. For 2013, we are aiming to reach a goal of \$100,000 and 100 trucks. For upcoming events in Atlantic Canada, please visit our website at [www.convoyforhope-atlantic.ca](http://www.convoyforhope-atlantic.ca).

### RUNNING THE ROME MARATHON IN MEMORY OF DINO MORELLO RAISES \$5,000



On behalf of the board of directors and staff at Lung Cancer Canada, we congratulate John Vettese on completing his first ever marathon in support of Lung Cancer Canada. In November 2012, John lost his father-in-law to lung cancer. In memory of Dino, and the

many other lives lost to lung cancer, we are truly grateful for your tremendous dedication.

"Given the statistics, it is my goal to bring more attention and focus to the cause of lung cancer and hopefully help make lung cancer prevention, research and treatment a priority," says John.



# Stereotactic Body Radiotherapy – Surgical Precision Without the Invasiveness of Surgery

**Anand Swaminath, MD FRCPC**

Radiation Oncologist, Department of Oncology, McMaster University, Hamilton

Radiotherapy is a common treatment for patients with lung cancer and is typically given in small daily doses for up to 3-6 weeks. Advances in technology for radiation planning and delivery have led to the introduction of stereotactic body radiotherapy (SBRT). SBRT differs from more conventional radiotherapy in that a very high daily dose of radiation is given over a much shorter time period (the treatment is usually completed in 3-8 sessions). The goal of SBRT is to mimic a surgeon's ability to remove a tumour by ablating it with radiation. SBRT is increasingly being offered to patients with early stage lung cancer who are unfit for surgery. It is becoming a popular option for these patients because of its potential advantages which include: non-invasiveness, convenience, minimal side effects and possibly long-term control of the cancer.

SBRT is performed in a similar environment as conventional radiation but requires sophisticated radiation planning and delivery equipment to carry out the procedure. Patients who are eligible for SBRT are planned using a CT simulation to identify the tumour, just as in any other radiation technique. However, other strategies in SBRT are required to ensure the lung cancer is treated as accurately as possible. Lung cancers can move with breathing, so accounting for tumour motion due to breathing is very important in SBRT planning. Some of the ways this can be accomplished are by performing a CT scan which looks at the tumour position in various phases of the breathing cycle, by inserting gold markers directly in and around the tumour so they can be seen by x-rays during the treatment, or by starting and stopping the radiation beam during a certain phase of the breathing cycle. Once the simulation is complete, the radiation oncologist works with the radiation therapists to plan the treatment using the CT simulation images and precisely mapping out the location of

the tumour target, as well as the organs at risk surrounding it. Because of the very high doses of radiation being used in SBRT, this step is extremely important to ensure the high doses of radiation are planned to the tumour, and neighbouring organs receive as little radiation as possible. SBRT can achieve these types of plans more successfully than conventional radiation because the dose beyond the target tends to drop off very rapidly. The total amount of radiation dose and timeframe for treatment is decided at the time of planning and largely depends on the size and location of the tumour within the chest.

Each treatment typically lasts 30-60 minutes. Side effects during treatment are usually minimal, with most patients experiencing some tiredness and occasional shortness of breath. Side effects in the months to years following treatment depend on the size and location of the cancer and may include shortness of breath, cough, difficulty swallowing, chest wall pain and rib fracture. Fortunately, most patients treated with SBRT do not experience any prolonged side effects. Still, patients should be followed by their radiation oncologist with CT scans at 3-6 monthly intervals to track response to treatment as well as any new symptoms.

Overall, SBRT is an option for patients with early stage lung cancer. However, it is important to discuss all options for lung cancer treatment with an oncologist as there are instances where SBRT may not be the most appropriate treatment. This depends on the clinical history of the patient, prior treatments and cancer status. If SBRT is an option, there may be an opportunity to enroll in clinical trials that are further evaluating the technique or comparing it to more standard techniques (surgery, conventional radiation), and patients should be encouraged to do so.



## Using Relaxation to Manage Shortness of Breath

Anxiety is an emotional state that increases muscle tension and sympathetic automatic nervous system activity. It can cause the body to react in a "fight or flight" response, which leads to increased blood pressure, heart rate and breathing, often leaving an individual feeling short of breath.

By relaxing, the parasympathetic nervous system is stimulated, which results in lowered blood pressure, heart rate and breathing—the opposite effect of the "fight or flight" arousal response. The body doesn't need to work as hard, tension decreases and breathing becomes easier.

Relaxation can be learned by individuals and applied to help prevent and reduce feelings of shortness of breath. The new relaxation videos added to the *Managing Shortness of Breath* series provide a number of short vignettes on relaxation techniques, including body awareness, progressive muscle relaxation and guided imagery. There is also a short video on how to use music to promote a feeling of relaxation.



# Celebration of Life



On January 13, 2013, the Lung Diagnostic Assessment Program (LDAP) at St Joseph’s Healthcare Hamilton (SJHH) held its second annual *Celebration of Life* honoring those affected by lung cancer and recognizing the necessity of hope and perseverance. Over 200 patients, supported by their families and friends, gathered to commemorate the day.

Dr. Yaron Shargall welcomed guests and spoke of the importance of screening, reducing tobacco use and early detection of the disease, which kills more than bowel, breast and prostate cancer combined.

Chris Sharland and Kathryn Loach spoke of the shock associated with finding out they had lung cancer even though they are in their 30’s and had never smoked a day in their lives. Helen Schlotter, another patient, affirmed that although she is in her 80’s, she still intends on doing a lot of living!! Other speakers included CEO of SJHH, Dr. Kevin Smith, and Dr. Janice Geisbrecht, Head of Oncology for the Walker Family Cancer Center in Niagara.

The day was marked with tears of joy, happiness and gratitude. Representatives from the Smokers Helpline, Wellwood Cancer Support and Lung Cancer Canada were on hand to offer support to the guests.

The annual Around the Bay Road Race benefitting SJHH, was held on March, 24, 2013 in Hamilton. Both Chris and Kathryn participated. At the reception Kathryn joked, “I’m going to run wearing a shirt that states: If you think you are tired, try doing this with one lung!”

Lung cancer remains a very lethal disease affecting approximately 23,000 people and causing 18,000 deaths in Canada annually. Although over 80% of lung cancer in Canada is still related to tobacco use, trends are changing with younger individuals, many whom have never used tobacco products, affected.

## Research-Grant Announcement

Lung Cancer Canada, our nation’s only non-profit dedicated to education, advocacy and research in lung cancer, has awarded \$50,000 to Dr. Sébastien Simard, Ph.D., Université Laval, for his proposal “A Prospective Study of the Quality of Life, Psychosocial Needs and Health-related Behaviours of Lung Cancer Patients.”



Dr. Sébastien Simard

“Contrary to other cancer groups, lung cancer survivorship has received minimal attention by the scientific community, partially due to little support and funding,” says Dr. Simard. “The Gabriella Memorial Hope Research Grant provides an exceptional opportunity to explore the psychosocial needs, the health-related behaviours and the

psychological mechanisms associated with quality of life and hope. This grant will allow us to elaborate on new recommendations and develop interventions to improve the quality of life of lung cancer survivors. For a clinical psychologist and a young researcher like me, this is really exciting!”

Lung Cancer Canada is grateful to the Micallef family for their dedication and

assistance in establishing our first-ever research grant. The grant is intended to promote a greater understanding of behaviours and common attributes of long-term survivors of lung cancer, including use of potential integrative and/or supportive therapies to improve patient outcomes. On behalf of the board of directors and the Micallef Family, we congratulate Dr. Simard.

**Next year, Lung Cancer Canada is establishing a lung cancer fellowship in collaboration with the Canadian Institute of Health Research (CIHR). Please visit [www.lungcancer.ca](http://www.lungcancer.ca) for updates on our research awards.**



# Lung Cancer Screening Guidelines: Fact vs. Fancy

**Michael R. Johnston, MD, FRCSC**

Director, Beatrice Hunter Cancer Research Institute; Atlantic Node Leader, Terry Fox Research Institute; Professor of Surgery, Dalhousie University

Ever since the National Lung Screening Trial (NLST) results were published<sup>1</sup> in 2011, a constant stream of guidelines have emerged from professional associations, societies, institutes and consensus groups. Each guideline has been assembled by a group of acknowledged authorities on lung cancer who systematically reviewed the available data. All of these guidelines indicate that those who meet the high risk criteria defined in the NLST (age 55-74, 30 pack per year or greater smoking history, current or former smokers who have quit for 15 years or less) should undergo low-dose CT (LDCT) scans yearly for three years. Furthermore, these scans should be performed only under very stringent conditions in healthcare facilities that have properly trained physicians (radiologists, thoracic surgeons, respirologists, pathologists) to interpret and act on the scan results. These are the facts as we know them today and if followed, we can reasonably expect to decrease the mortality in those found to have lung cancer by about 20%.

Many organizations have taken this opportunity to go beyond the facts and add to their guidelines other groups of individuals who may be at higher risk of developing lung cancer than the general population, but where a benefit from screening is still unproven. For example, the American Association of Thoracic Surgeons (AATS) recommends LDCT screening for people 50 years of age or older with at least a 20 pack per year smoking history, regardless of if or when they quit, as long as they have at least one other lung cancer risk factor such as chronic obstructive pulmonary disease (COPD), occupational exposure or a family history of lung cancer<sup>2</sup>. These recommendations mirror those of the National Comprehensive Cancer Network, a US government supported agency<sup>3</sup>. But the AATS goes further in recommending that screening be performed yearly until age 79, as long as the individual is fit enough for treatment if a lung cancer is detected.

Of interest, the International Association for the Study of Lung Cancer (IASLC), which has representation from just about every country in the world, has not issued specific guidelines for screening. Instead, its report<sup>4</sup> stresses the need for more investigation into selecting the proper population to screen, defining the best way of managing suspected lung cancer nodules, defining how long individuals should be screened and what makes sense in terms of cost-effectiveness.

So where does that leave us Canadians? Fortunately, many of the very crucial questions posed by the IASLC and other organizations may be answered by our own Pan-Canadian Lung Cancer Early Detection Study, which since 2008 has followed over 2,500 high risk individuals in eight centres across Canada. This study is funded by the Terry Fox Research Institute and the Canadian Partnership Against Cancer (CPAC)<sup>5</sup>. Recently, a two-year extension of the study has been approved and will be partly funded by Lung Cancer Canada. This will help us answer the questions of how often and how long people need to be screened. And of great importance here, as compared to the US, it will produce an economic assessment of the cost for lung cancer screening in our tight budgeted, provincially managed healthcare system. Until we have this information, the NLST screening criteria is the only one with a proven track record, although funding from provincial healthcare authorities is not yet available. Hopefully, demonstration projects, as recommended by IASLC, will be set up in each province under the guidance of the Pan-Canadian Lung Cancer Screening Network, a working group representing all of the provinces and territories and sponsored by CPAC.

Our greatest fear is that cancer screening will be performed in an unregulated and opportunistic fashion without proper safeguards or expertise. This will be both a huge burden to the healthcare system and subject people to all of the inherent risks of screening with little, if any, benefit.

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