



FACES OF LUNG CANCER
#HOPEUNITES | 2017 REPORT



LUNG
CANCER
CANADA

THE FACES OF LUNG CANCER REPORT

NOVEMBER 2017

#UNITED AS ONE VOICE

2017 LUNG CANCER CANADA REPORT FOREWARD

Lung cancer is a global epidemic. Every year, it headlines as the most common cause of cancer death, worldwide! The ravage of this disease is not unique to Canada, but something that connects all borders and crosses every socio-economic segment. It's simple; lung cancer is an issue that touches everyone!

Today, a patient diagnosed with lung cancer in Canada must navigate a challenging and inconsistent framework of processes that can lead to delays and limits in access. Science and technology are moving faster than we could have ever imagined. We need to anticipate future advancement and new systems, and processes need to be road-mapped to enable better access for patients.

Each diagnosis sets into force the journey of a lifetime. Unfortunately, there is no state-of-the-art technology to navigate this complicated maze, no GPS, it becomes an uncharted journey for so many, for no reason. With every step along the way there are too many stories to count, children who have lost parents to the

disease, a widow who mourns the loss of her husband – the reality of lung cancer is real and never forgotten.

The Canadian lung cancer patient community is witness to the power of innovation, but our regulatory environment also needs to innovate or else we will continue to fail patients with unnecessary delays and serious access issues. The sharing of best practices and building upon already achieved milestones is one of the solutions. Collectively, the lung cancer community of patients, physicians, nurses and family members can make a difference. We also need to look to our international neighbours for best practices in patient access. For the first time, life-saving medicines in lung cancer can dramatically improve the prognosis for so many patients. We cannot ask them to wait for hope to be realized.

#HopeUnites and the patient-voice embodies the spirit of partnership and we encourage the community in Canada to evaluate the successes and learnings from all corners of the globe to make innovative changes and strategic differences in how we approach this devastating disease.

– **Canadian Lung Cancer Patients**

LUNG CANCER PATIENTS AND FAMILIES DESERVE TO BE SUPPORTED

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PARTNER

INTRODUCTION

#KEEPINGITREAL OVERVIEW

#HopeUnites. It is the cornerstone of the lung cancer story in Canada. Hope drives patients who face a battle of their lives. Hope fuels families as they support their loved ones through diagnoses and treatment. Hope inspires the researchers diligently working to find a cure. Hope is the common denominator for everyone that is touched by lung cancer. Despite 2017 statistics that show more people will die of lung cancer (21,700) than from colorectal, breast and prostate cancers combined (18,500)ⁱⁱ, there are many milestones to celebrate.

Screening

The collective achievements of researchers and advocates led to a national guideline recommending routine screening for those Canadians who fall into high-risk categories. This was a major step forward and has immediately led to the beginning of various provincial pilot-screening programs. This means that more Canadians will be diagnosed early and have improved chances of survival and quality of life.

New treatment options

Two more targeted treatment options were approved for use in Canada. This is great news for patients who need choice when it comes to drug therapy, but will they ever be able to access

them? That is the real question and an important theme in this year's Faces of Lung Cancer Report. Rapidly advancing biomarker testing and diagnostics are stretching the limits of how we evaluate drugs and their effects on various tumour types. Emerging science is having a profound impact on the lung cancer story and our next goal is to make the connection between innovation and access for Canadians. New systems have been tested. Improved processes have been identified. The evidence speaks for itself. It's time for a Canadian lung cancer access reform.

We have a history for inspiring change. Efforts in the 1960's to educate Canadians about lung cancer risks and the importance of screening and early detection have worked. Canada has seen a reduction in the incidence of lung cancer in men since the mid-80s and there has been a consistent decline (1.9% per year since 1992)ⁱⁱⁱ. The story is not as positive for Canadian women, but progress is still being made. It wasn't until the mid-1980s when drops in the rates of smoking were observed in women, suggesting that in the coming years, incidence rates will decline and the story will enter a new chapter. This is an example and an important reminder that change takes time.

**LCC BELIEVES THAT
#HOPEUNITES
AND A LOT OF
DETERMINATION
WILL DRIVE US
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LIVING WITH
LUNG CANCER.**

THE FACES OF LUNG CANCER REPORT FOR 2017

The lung cancer community understands the harsh realities of this disease, they are not blind to what is at stake here. Determined to re-route a devastating journey, driven by optimism and hope, it is important to find solace in the achievements and target the obstacles that continue to threaten Canadians, the next generation of the Faces of Lung Cancer.

Lung Cancer Canada has been a part of the journey for so many and the organization will continue to be a constant support as we move the agenda forward. It is about positively impacting the lives of every patient, family member and caregiver. LCC stands with patients to improve awareness, stigma, research and access – these are the targets and every Canadian deserves a fair chance to beat lung cancer.

Casey Cosgrove
Burlington, Ontario





REPORTS

LUNG CANCER IN CANADA

#ACCESTOSCREENING SCREENING UPDATE

The lung cancer story saw a major triumph in 2016, when the Canadian Task Force on Preventive Health Care released a new guideline recommending annual lung cancer screening in high-risk adults ages 55-74.^{iv} Based on a national lung cancer screening trial that evaluated 50,000 participants, the life-saving power of screening could no longer be ignored. After the six-year follow-up, researchers identified a 20% reduction in lung cancer deaths - this was a huge revelation considering in other cancers like breast, the average reduction rate is 3-4%. There was also a 7% reduction in 'all case' mortality with patients dying less of other diseases and conditions. As a comparison, it takes 320 lung cancer screens to prevent one lung cancer death while it takes 600 colonoscopies to detect one case of colon cancer.

There is no question that screening saves lives. As a community, we need to look at the success in other cancers such as breast, colon and cervical who have routine screening programs in place and the survival statistics to demonstrate how critical it is. The positive screening results seen in other cancers are a huge sign of hope for the lung cancer community who know that an early detection means there is a better chance for curative treatment. The current reality of diagnosis is frightening. Almost half (48%) of lung cancer diagnoses are made when the cancer is at stage 4, the most advanced and aggressive stage. A further 27% of lung cancer diagnoses are made at stage 3, which is still far too late. There are also a number of factors that exacerbate disease detection in unacceptable late stages of the disease.

Following the Task Force's recommendation, many provinces were quick to establish pilot programs in key locations. The up and running pilot

programs are evaluating the process carefully, ensuring that it is effective and that the patient experience is top of mind.

Ontario is the first province in Canada to have a government funded lung cancer screening pilot program. In British Columbia and Alberta, cancer or hospital foundation-funded pilot projects are also in place for those patients that are high risk. Together, Ontario, British Columbia and Alberta use a lung cancer risk prediction tool to identify high risk individuals between the ages of 55 to 80 for LDCT screening. Eligible candidates must meet a pre-defined 6-year lung cancer risk because screening only benefits those with sufficiently high risk for lung cancer.

In considering the Ontario test sites, the panel wanted to ensure the provincial framework was nimble enough to accommodate tweaks, but remain as a solid model for implementation across the country. The criteria for the test sites were high, but ensuring it would be equally successful in large and remote communities was key. The Ottawa Hospital and Renfrew Victoria Hospital, Health Sciences North in Sudbury (3 hospitals) and Lakeridge Health in Oshawa were selected for the three-year test pilot.

“Local adaptation is paramount. Ensuring the success of protocols in varying communities is key to having a positive impact on the disease. It is the first program of its kind in Canada, so we know that we may need to make adjustments along the way, but we've started from a very good point and I am encouraged by the results so far.”

- **Dr Gail Darling**, Cancer Care Ontario Lead for High-Risk Lung Cancer Screening.

In addition to the clinical benefits of the pilot program, there is a huge opportunity to identify cost efficiencies. In the absence of a structured screening framework the challenges when it comes to cost are too many to cite. The Ontario pilot program is encouraging and estimates point to long-term cost savings. Cancers that are detected early have better chances for curative treatment. When lung cancer is detected in late stages the costs of long-term therapy are substantial, early identification has a ripple of effects.

“We know a lot about lung cancer already and the work being done in the screening pilot is adding to our wealth of knowledge here in Alberta. Early detection is key and will reduce late stage diagnoses by up to 20% and routine screening can increase a patient’s life expectancy by up to 10.5 years. Not only will the investment demonstrate positive clinical outcomes, but we can anticipate a cost-neutral model when the need for expensive late-stage drugs diminishes”

- **Dr Stephen Lam**, MD, FRCPC

Chair, Lung Tumor Group & Judah Leon Blackmore Chair,
BC Cancer Agency Professor of Medicine University of
British Columbia.

In many cases, a patient can receive test results, diagnosis and schedule next appointments on the same day. To put that into perspective, waiting for results from routine mammography scans can sometimes take up to a month. They are also connected with a nurse navigator who becomes their main point of contact to book their next appointment, discuss tests,

concerns and sometimes, just someone to talk to. The Ontario screening program is proof of what investment can do. Patients are not waiting hopelessly. They are experiencing the power of innovation and being given the best chance to beat lung cancer.

Lung cancer screening is not a test but a process. It involves identifying candidates with sufficient lung cancer risk to benefit from the screening. Special CT scan protocols can define small spots and uses less than one-fifth of the regular radiation dose. There is a standardized pathway to manage abnormal findings to minimize harms from repeat tests. Those might include CT imaging with regular dose CT or PET scans, biopsy or surgery for lesions that turn out to be non-cancerous. In addition, screening programs include the provision of smoking cessation services to participants who are still smoking. For provinces that do not yet have a screening program, self-paid ad hoc LDCT screening is not recommended.



Dr Stephen Lam

Vancouver,
British Columbia

#BEATLUNGANCER – STEPHEN ARONSON

Faces of Lung Cancer Patient Story

Meet Stephen. He is a proud grandfather and husband living in Ottawa, Ontario. He is 67 years old. Life took a sharp turn six years ago when he was diagnosed with lung cancer, but his story is one that inspires hope and motivates early intervention.

Stephen was no stranger to the disease since his father passed away from lung cancer a number of years ago. He knew the risk factors. He saw the terror of the disease. As a former smoker with a family history, Stephen knew it was something he needed to be proactive about.

It was the winter of 2010 when his story would detour. Stephen saw an ad in the local newspaper for a screening study looking at high-risk Canadians. Responding to this ad would change his life forever. He enrolled into the study and immediately had a number of CT scans. It was the second scan that would identify a small lesion. Stephen's life flashed before his eyes.

As a loving husband and grandfather, it was important for Stephen to be honest about the diagnosis. Lung cancer was scary. It was a shock for his family who looked at him as a pillar of strength,

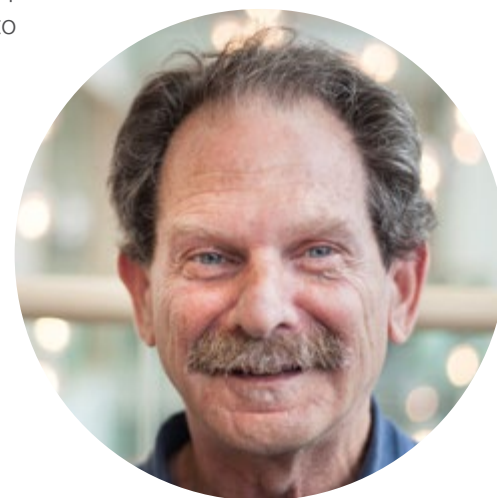
someone who was 'unbreakable'. The family united and became their husband and father's core source of support. The Aaronson family was ready to take every step of this journey, together.

Waiting was the hardest part. Stephen was strong and optimistic, but the delays between appointments were a significant challenge for him, mentally and physically. Surgery was scheduled and his physicians gave him a positive prognosis. The support he received was a tremendous amount of hope.

It has been seven years since Stephen was first diagnosed. He is still cancer free and credits his survival to the power of screening. Now a champion of screening, Stephen wants other Canadians to have the same hopeful story.

"We're not here for just ourselves, but for our family and friends."

LCC BELIEVES THAT ALL STAKEHOLDERS NEED TO PROVIDE GUIDANCE TO DEVISE NEW AND EFFICIENT DELIVERY SYSTEMS OF DIAGNOSTICS AND TREATMENT IN CANADA.

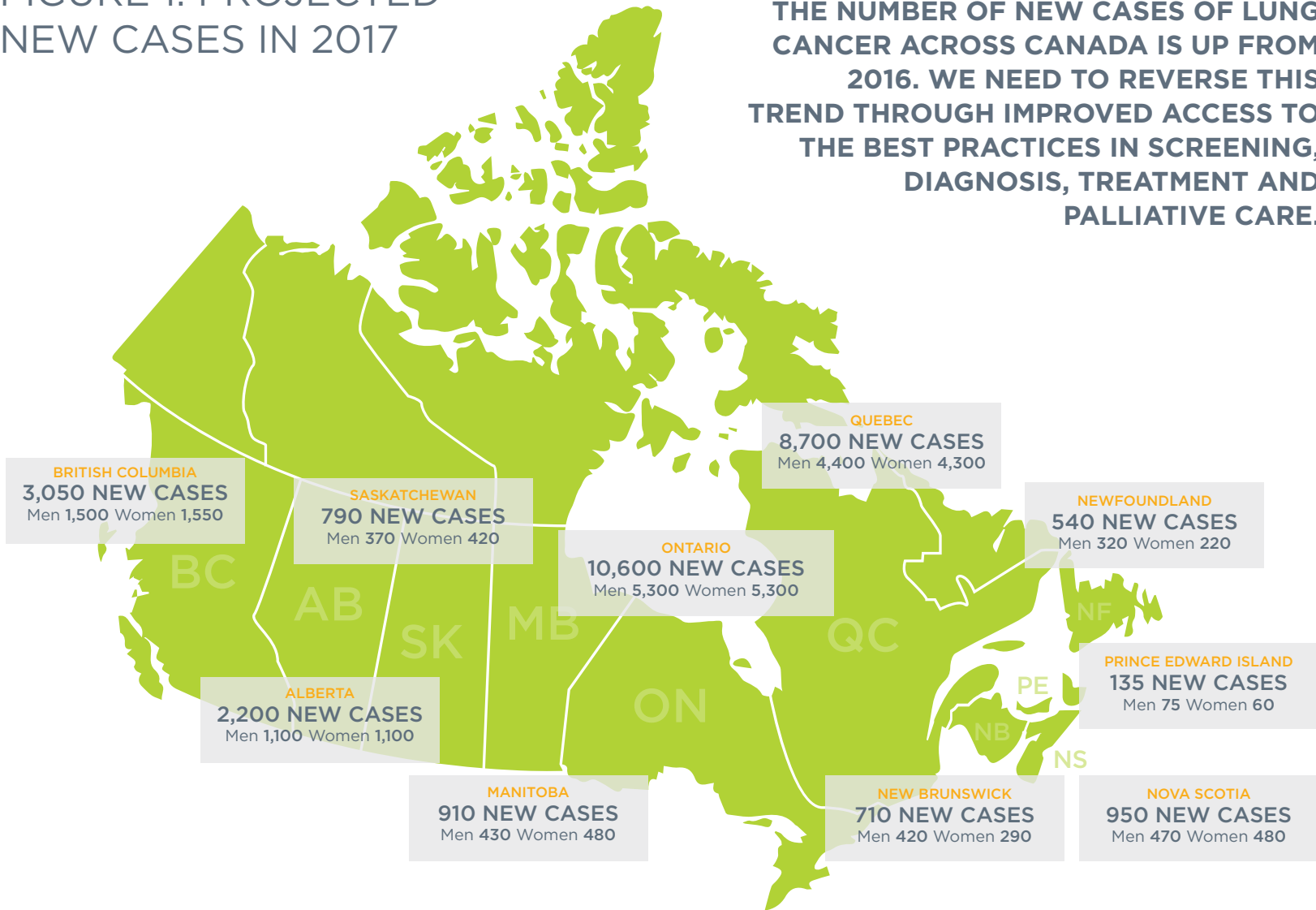


Stephen Aronson
Ottawa, Ontario

#LUNGCANCERACROSSCANADA

FIGURE 1: PROJECTED NEW CASES IN 2017

THE NUMBER OF NEW CASES OF LUNG CANCER ACROSS CANADA IS UP FROM 2016. WE NEED TO REVERSE THIS TREND THROUGH IMPROVED ACCESS TO THE BEST PRACTICES IN SCREENING, DIAGNOSIS, TREATMENT AND PALLIATIVE CARE.



#LUNGCANCER411

AN OVERVIEW OF LUNG CANCER IN CANADA

Putting the lung cancer story into numbers can be quite dramatic.

It is an eye opening exercise to see how sweeping this disease is. More Canadians are expected to die from lung cancer (21,100 in 2017) than from colorectal, breast and prostate cancers combined (18,500 in 2017).^v Canada's deadliest cancer has a frightening data profile with 78 Canadians diagnosed daily and another 58 dying from the disease, every day.^{vi} The statistics tell it all. Lung cancer is an epidemic in Canada with a devastating impact on the lives of patients, but also remember the family, friends, and caregivers who ride alongside the lung cancer journey.

- ▶ **28,600** Canadians will be diagnosed with lung cancer. This represents 14% of all new cancer cases in 2017.^{vii}
- ▶ **26%** Lung cancer is the leading cause of cancer death for both sexes, accounting for approximately 26% of all cancer deaths in both males and females.^{viii}
- ▶ **21,100** Canadians will die from lung cancer. The rates of women being diagnosed increased in almost every province in 2017.^{ix}
- ▶ **14,400** Men will be diagnosed with lung cancer and 11,100 will die from it.^x
- ▶ **14,200** Women will be diagnosed with lung cancer and 10,000 will die from it.^{xi}

How Do The Provinces Measure Up?

- British Columbia and Alberta have the lowest lung cancer incidence rates in Canada for both males and females.^{xii}
- Quebec and Nova Scotia have the highest lung cancer rates for women while Newfoundland and Labrador and Quebec have the highest rates for men.^{xiii}
- Ontario and Quebec have the highest mortality rates in the country, followed by BC.^{xiv}



#ACCESTOAWARENESS LUNG CANCER & STIGMA

The stigma experienced by patients with lung cancer is undeniable.

Stigma and shame are inexplicably linked, and part of the lung cancer story. As a community we recognize the evolution and relationship that stigma has on both patients and their families, but we are hopeful that ongoing efforts to educate Canadians will close this ugly chapter. The 'shame game' is a dangerous thing when a patient is already struggling to remain positive and channel energies into survival. The presence of intense stigma has been linked to a number of negative health outcomes.^{xv} The majority of patients with lung cancer report experiencing stigma, often related to guilt, regret, perceived blame and other negative beliefs about smoking history.^{xvi}

Anti-smoking campaigns focus on the link between tobacco and lung cancer. However, smoking is linked to many other diseases such as heart disease and stroke. The truth is, if you have lungs you can get lung cancer. This includes current smokers, those that have worked hard to quit, and never-smokers. No one deserves lung cancer and yet lung cancer patients face stigma and judgment that they have a self-inflicted illness. Is the tobacco agency not more to blame for making a highly addictive product? Canadians are known for an open attitude and one that does not judge based on sexuality, religion, gender or age. Why are we judging individuals based on their cancer type?

If we put the facts in place, the notion that if you don't smoke, you are worry free from cancer is a common misconception caused from misguided campaigns in the media. This leads to a number of complications such as late diagnosis and poor rates of survival - lung cancer can affect everyone, not just smokers. In fact, as many as 15 percent of lung cancer patients are life-long non-smokers, and 50 percent of patients diagnosed with lung cancer have quit before the time of diagnosis.^{xvii} The rates of never-smokers with lung cancer is also on the rise and a re-focus of media reporting is required to align with a shifting demographic of patients being diagnosed.

It is well documented that stigma is associated with negative psychosocial and medical outcomes, including delayed diagnoses, poor quality of life, poor communication between the patient and their physician and increased mortality. Studies that look at stigma and the long-term outcomes of cancer are few and far between, but anecdotally, there is a great deal of real world evidence linking stigma to reduced treatment adherence and psychosocial distress.^{xviii}

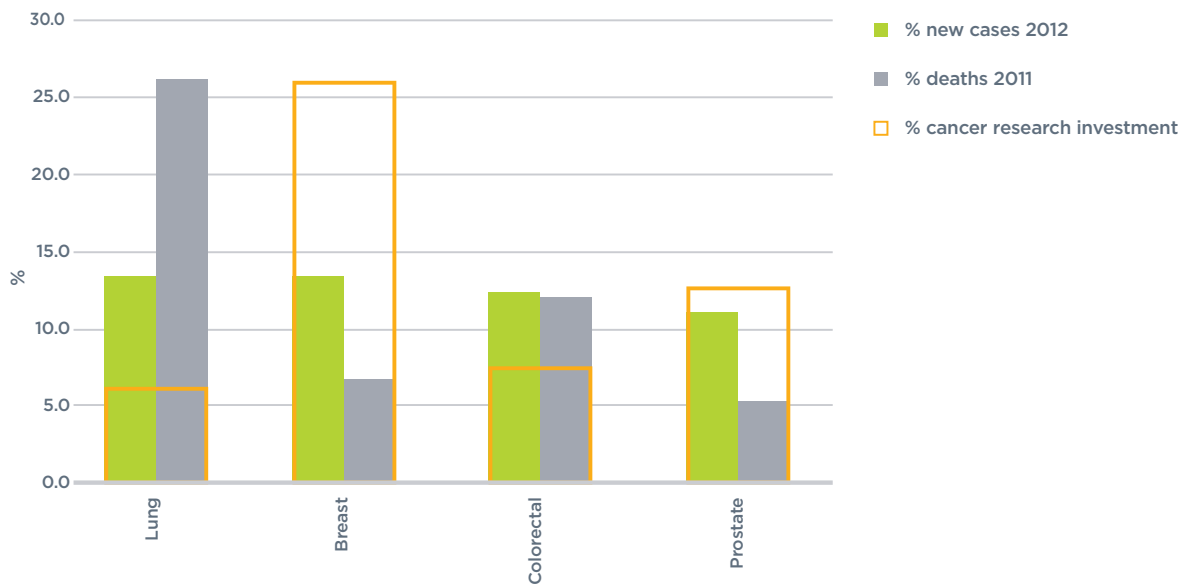
Although lung cancer is by far the largest cancer killer, it is also the least funded. Compared to others like breast and prostate, lung cancer receives only a fragment of the investment and this is undoubtedly linked to the heavy stigma around the disease.

Deprived of investment, the lung cancer community is limited in our ability to change the story, quickly.

Armed with evidence about the negative impacts of stigma, Lung Cancer Canada believes a new approach to public health education and awareness is required. Campaigns that educate Canadians about the risks, but counter the ongoing issue of stigma can help the fight against lung cancer 'turn a page' where the focus can move from blame to support.

LUNG CANCER RECEIVES ONLY A FRAGMENT OF THE INVESTMENT AND THIS IS UNDOUBTEDLY LINKED TO THE HEAVY STIGMA AROUND THE DISEASE.

Figure 2 - Proportion of research investment in Canada for select cancers relative to the distribution of new cases and cancer deaths



#BEATLUNGANCER – DEBI LASCELLE

Faces of Lung Cancer Patient Story

Meet Debi. She's 60 years old and lives in Ottawa, Ontario. Debi couldn't have fathomed how her life would change in November of 2010. At the time, a large study was in development to evaluate Canadians who fell into the 'high risk' category for lung cancer and Debi enrolled. It would be this step in Debi's story that changed her fate forever. She underwent several tests in preparation for the study and the presence of lung cancer was detected.

Lung cancer ran in the family, in fact Debi's father died of the disease. She had been a smoker more than twenty years ago, but Debi knew the risks. Now, she quickly moved into a different chapter of her life, one that would heavily influence her perspective, forever.

Debi accepted her lung cancer diagnosis. She knew she had to push through this and not focus on the 'why this is happening', but on the 'why I'm going to beat this'. She made herself very aware of her disease, but placed a great deal of trust with her physician and support team, not something all patients can do.

Debi's strength saw her through a successful lobectomy and a positive prognosis from her physician. She witnessed first-hand what someone battling with cancer faces. Long waits in between

appointments and insurmountable anxiety were key fixtures of her every day.

Something Debi was not expecting was the pressure that stigma had. She was open with her family about her disease and what she was going through, but held back with so many others. She felt the unsympathetic feelings from countless conversations who still see lung cancer as a disease that is self-inflicted, something Debi was determined to change.

Despite dealing with lung cancer herself, Debi was also acutely aware of what the disease was doing to her family. Debi has been married to John for twenty-seven years. At first glance John's gruff exterior might make you think not much bothers him. Debi's cancer was a devastating time, but through the couple's love for one another, they were stronger together.

A regular routine of yoga has kept Debi's mind, body and soul alive and well. A self-admitted planner and organizer, she now looks at life in the present. She lives for today and hope brings tomorrow.

“I do hope to find things in every day that make me laugh, that make me smile, that touch my heart. I'd wish for everyone to have those hopes, regardless of their health.”

LCC BELIEVES LUNG CANCER IS NOT A STORY TOLD ONLY IN NUMBERS. ALTHOUGH THE HUMAN TOLL IS SIGNIFICANT, IT GIVES THE COMMUNITY THE STRENGTH TO CHANGE THE STORY'S ENDING.



Debi Lascelle
Ottawa, Ontario



PART 3

LUNG CANCER TREATMENT
APPROVALS AND ACCESS

#ACCESSTOTREATMENT THE “INVISIBLE” CANCER

The current system, through which Canada evaluates and approves life prolonging cancer drugs, is flawed. This has clearly been established in previous Lung Cancer Canada reports including highlighting the many lung cancer patients who have died waiting for treatments that could have had a profound impact on the progression of their disease. Along with extreme access issues, all cancer types carry the burden of a system and infrastructure that is failing the patients they are trying to save. Unlike other cancers with improving survival rates, the lung cancer story is unique. The lack of a national screening program and intense stigma are key factors that result in late stage diagnoses. A diagnosis made at stage 3 or 4 significantly diminishes survival rates because most of these patients do not have the time to wait for lengthy drug approval timelines and provincial access. As the system struggles, patients with lung cancer continue to die and there is an ever-swelling sense of mounting impatience.

According to a new research analysis published in the *Journal of Canadian Health Policy*, Canada has been described as a country with one of the most restricted access frameworks for publicly funded cancer drugs.^{xx} How can a country known around the world for its top-notch healthcare and quality of life fall so far behind the rest of the world? Canada is an epicentre of innovation and a country many flock to for individual rights and freedoms yet dramatic changes are needed now or patients will continue to die, helplessly. The analysis looked at provincial drug insurance coverage delays for a number of oncology drugs to determine the number of potential patients impacted and the economic costs of these delays – the conclusions only cement a mantra for change and reform.

Outlined in the report, Canada falls behind in oncology drug approvals in a number of areas. First, drugs are often submitted to Health Canada for approval after the FDA and European Medicines agency.^{xx} Thirty-five percent of oncology drugs approved in both Canada and the United States between 1992 and 2011 were submitted to the FDA more than six months before being submitted to Health Canada.^{xxi}

The second area where Canada falls short is our slow regulatory review process. Median review times for oncology drugs approved in Canada between 1992 and 2011 was 13 months compared with a median time for the United States of 8.9 months. The median approval time of oncology drugs in the United States more than halved between 1992–2001 and 2002–2011 from 12.7 to six months. A reduction in the median approval time of oncology drugs also occurred in Canada, but only from 14 to 12.3 months, and the proportion of oncology drugs submitted to the FDA more than six months before being submitted to Health Canada increased from 29.2% in 1992–2001 to 39.4% in 2002–2011.^{xxii}

The delays for life saving cancer treatments don't end after receiving approval from Health Canada. Market authorization is just the start of a new series of challenges. In the US, once the FDA approves a drug, insurers are quick to cover and patients see the benefit of this rapid process with access to innovations that can be lifesaving. For Canadian patients, access to these treatments are held up by health technology assessments such as clinical and patient benefit, pricing reviews and negotiations, and depending on which province you live in, possible further fiscal scrutiny. What is this analysis telling us? Basically, Canadians wait longer for drug approvals, reimbursement/access compared

to their US peers and depending on where you live in Canada due to an inconsistent framework, a patient may wait even longer. An example of a recent study showed the median time between Health Canada approval and provincial reimbursement listing of cancer drugs approved between 1989 and 2012 was twice as long in Newfoundland and Labrador (21.6 months) as in British Columbia (10.8 months).^{xxiii}

**5,000 PATIENTS
WERE IMPACTED
BY APPROVAL AND
ACCESS DELAYS.**

The analysis indicates that according to previous assessments of provincial access to five oncology drugs, over 5,000 patients were impacted by approval and access delays.^{xxiv} Five thousand faces of lung cancer! Five thousand stories of lung cancer! Factor in the number of family and caregivers and the human toll of an infrastructure that has not evolved is unacceptable.



#BEATLUNGANCER – PAUL ROSENBLATT

Faces of Lung Cancer Patient Story

Meet Paul. He is a 39-year-old proud dad and loving husband living in Hamilton, Ontario. In the blink of an eye, Paul's reality changed. He characterizes the change as "one month I was skiing on a family vacation, the next month I had lung cancer". Paul's story reinforces the importance of finding your source of hope; after all, according to him this is what gives you the power to charge forward.

Most Canadians maintain a stereotypical image of a person with lung cancer. Paul represents one of thousands who has lung cancer, never smoked a day in his life, and lived a healthy and active lifestyle. Because of Paul's background, he didn't fall into a high-risk category. It was January of 2016 and Paul just got over a cold he caught from his son, a routine occurrence with young children. A persistent cough and respiratory infections prompted a CT scan. There was a mass. It was stage 4 and it had spread throughout his body, including the brain. It was at that moment when Paul needed a shred of hope to remain positive.

Radiation was the first step to shrink the brain metastases. It was successful and Paul saw some optimism. The hardest part was the waiting,

he recalls. Anxiously awaiting updates from the hospital. Anything. Wondering. Paul's next interaction with his medical oncologist would change everything for him.

The disease was in a late stage, but based on the marker-testing showing it was ALK+, his oncologist revealed news of great promise. A new-targeted treatment, which would have the greatest opportunity to treat his disease, was in clinical trials at the time. After process delays, Paul was finally enrolled. The treatment was successful and began to have an impact on the progression of the disease.

Paul's story teaches that the face of lung cancer is not always who you think. It reinforces a need to improve access to new cancer drugs, since patients don't have time to wait. They have families and lives to protect and as Canadians they should have every opportunity to beat such a devastating disease.

"With nothing to hold onto, hope is really hard to find. Find one thing that gives you hope and let it carry you through. It is all you need".

LUNG CANCER SHOULD NOT BE SEEN AS A RACE OR AN INDICATOR OF WHICH COUNTRY IS DOING A BETTER JOB. LCC BELIEVES BY LOOKING AT SUCCESS IN OTHER AREAS, WE CAN BUILD ON AND IMPROVE THE LIVES OF PATIENTS IN CANADA.



Paul Rosenblatt
Hamilton, Ontario

#ACCESSTOFUNDING

WHO PAYS FOR LUNG CANCER?

The spirit of collaboration and the sharing of best practices can drive the lung cancer agenda forward, faster. Lung Cancer Canada together with the wider community strongly believes that we need to identify other countries where access to treatments is meeting the needs of patients. Canada is a country with so many positives, so it is okay for us to admit that we have work to do when it comes to patient access for new and effective lung cancer treatments. We are not perfect and that is okay. Awareness of the imperfections and an openness to change is what can set us apart as a nation and have profound impacts on the lives of patients.

Profiled in last year's report, Lung Cancer Canada conducted its own comparative analysis of lung cancer drug approvals in Canada, versus to the US. Specifically, the analysis investigated the time it takes for lung cancer drugs to become publicly reimbursed in each province. The analysis was updated this year. We chose to use the FDA approval date as a baseline for comparison, as this represents a milestone in the recognition of a treatment's efficacy and is commonly the earliest international approval of a new drug. It is important to note that clinicians, through participation in trial and/or results presentations at conferences and publications, may recognize a treatment's efficacy much earlier. Therefore, using the FDA approval date as the anchor point is a conservative reflection of the true wait times. The comparison was shocking and clearly demonstrated the urgency to improve Canadian pathways of drug approvals to benefit patients faster. Unfortunately, the Canadian lung cancer story hasn't changed much since last year's Faces of Lung Cancer report - the progress has been dismal.

An example of a drug access issue that many Canadian lung cancer patients are currently struggling with is with alectinib (Alecensaro). Despite the fact that the treatment was approved in 2015, a final recommendation for its use in second line is still pending. The provinces continue to make these life-changing medicines inaccessible and unfortunately, cost is a driving factor. (See Figure 4) To further complicate the timely delivery of emerging cancer drugs an inter-provincial organization of provincial/territorial cancer agencies/programs engaged in cancer control called CAPCA (Canadian Association of Provincial Cancer Agencies) has initiated a new advisory committee to look specifically at the affordability and impact on budgets, from a pan-Canadian basis. The Cancer Drug Implementation Advisory Committee (CDIAC) provides an expert recommendation for the provinces when evaluating a new cancer treatment. Although the attention of senior oncology experts is always valued, concerns that new and effective treatments will be reviewed based on clinical and financial analysis is cause for concern. The impact of lung cancer is far reaching. Beyond numbers on a page, patients need to be consulted as part of any evaluation process to ensure the 'human' aspect is considered. As advocates for the lung cancer community, LCC urges a closer examination of this process and welcomes an invitation to provide the patients' perspective.

Although access to already approved treatments continues to be a dominant issue, new drug developments illuminate hope for many patients and their loved ones. Two new options were approved for use in Canada in 2017, so far. Combination treatment dabrafenib (Tafinlar®) plus trametinib (Mekinist®) was approved for use to treat BRAF V600-posi-

tive metastatic non-small cell lung cancer (NSCLC) after prior systemic therapy. About 1 - 2% of NSCLC patients are BRAF positive. At the time of this report, it received an initial negative funding recommendation from the Pan-Canadian Oncology Drug Review (PCODR). This is despite the dramatic overall response rate in comparison to chemotherapy. Unless this decision is reversed, BRAF V600 patients in Canada may never have access to this therapy. Even more troubling is the implication of this decision on personalized medicine in Canada. It is recognized by clinical experts and international associations that targeted therapies allow for better patient outcomes. Decisions such as this one run contrary to best clinical practices and means that Canada is taking a step backwards in terms of personalized medicine.

A second beacon was the approval of pembrolizumab (Keytruda®). It joins nivolumab as an immunotherapy option for NSCLC patients. Pembrolizumab was approved for patients with metastatic NSCLC whose tumours express PD-L1 as both a first-line option and as a second-line option for patients who have disease progression on or after platinum containing chemotherapy. Immunotherapies are innovative

treatments that can improve the survival of NSCLC patients who have not responded to traditional therapies. At the time of publication of this report, nivolumab is reimbursed in all provinces with the exception of PEI. Keytruda is still being held up in the regulatory process, while patients and physicians want access right now.

Patients with lung cancer do not have the luxury of time. Lung cancer is different from other cancers. Patients are diagnosed later. This is a fact, and the mortality rates for the disease validate this statement. Lung cancer patients have no time to wait! With each passing day the stakes increase and the sense of urgency heightens. It is time to acknowledge that we are operating within a system that is broken: a system that is not serving those in need. Patients will continue to die waiting until the required treatment approval and access reform is made.

We need to act now!



Figure 3 - Date of FDA approval to Health Canada approval

| DRUG Generic name (brand name) | INDICATION | FDA APPROVAL DATE | ADDITIONAL DAYS UNTIL HEALTH CANADA APPROVAL DATE | pCODR Status | Phase Data Used |
|---|--|-------------------------|--|---|-----------------------|
| afatinib (Giotrif®) | For the first line treatment of epidermal growth factor receptor (EGFR) mutation positive, advanced non-small cell lung cancer (NSCLC) patients | July 12, 2013 | November 1, 2013 (112 days) | Final Recommendation May 2, 2014: Recommended pending cost effectiveness | 3 |
| alectinib (Alecensaro®) 2nd line* | As monotherapy for the treatment of patients with anaplastic lymphoma kinase (ALK) positive, locally advanced (not amenable to curative therapy) or metastatic NSCLC who have progressed on or are intolerant to crizotinib until loss of clinical benefit | December 11, 2015 | September 29, 2016 (293 days) | Pending | 3 |
| alectinib (Alecensaro®) 2nd line with central nervous system (CNS) metastases | As monotherapy for the treatment of patients with ALK positive, locally advanced or metastatic NSCLC who have progressed on or are intolerant to crizotinib and have central nervous system (CNS) metastases | December 11, 2015 | September 29, 2016 (293 days) | Final Recommendation: Not recommended | 3 |
| ceritinib (Zykadia®) 2nd line | For treatment as monotherapy in patients with ALK positive locally advanced (not amenable to curative therapy) or metastatic NSCLC who have progressed on or who were intolerant to crizotinib | April 29, 2014 | March 27, 2015 (332 days) | Final Recommendation December 3, 2015: Not Recommended | 2 |
| ceritinib (Zykadia®) Resubmission 2nd line | For treatment as monotherapy in patients with ALK positive locally advanced (not amenable to curative therapy) or metastatic NSCLC who have progressed on or who were intolerant to crizotinib | April 29, 2014 | March 27, 2015 (332 days) | Final Recommendation March 21, 2017: Recommended, pending cost effectiveness | 3 |
| crizotinib (Xalkori®) 2nd line | As monotherapy for use in patients with ALK positive advanced (not amenable to curative therapy) or metastatic NSCLC | August 6, 2011 | April 25, 2012 (263 days) | Final Recommendation October 4, 2012: Not Recommended | 1/2 |
| crizotinib (Xalkori®) Resubmission 2nd line | As monotherapy for use in patients with ALK positive advanced (not amenable to curative therapy) or metastatic NSCLC | August 26, 2011 | April 25, 2012 (243 days) | Final Recommendation May 2, 2013: Recommended, pending cost effectiveness | 3 |
| crizotinib (Xalkori®) Resubmission 1st line | As monotherapy for use in patients with ALK positive advanced (not amenable to curative therapy) or metastatic NSCLC | August 26, 2011 | April 25, 2012 (243 days) | Final Recommendation July 21, 2015: Recommended, pending cost effectiveness | 3 |

*At the time of publication the FDA was reviewing alectinib for 1st line indication

Continued... Figure 3 – Date of FDA approval to Health Canada approval

| DRUG Generic name (brand name) | INDICATION | FDA APPROVAL DATE | ADDITIONAL DAYS UNTIL HEALTH CANADA APPROVAL DATE | pCODR Status | Phase Data Used |
|--|---|---|--|--|-----------------------|
| dabrafenib (Tafinlar®) + trametinib (Mekinist®) 2nd line | In combination for the treatment of patients with advanced NSCLC with a BRAF V600 mutation and who have been previously treated with chemotherapy | June 22, 2017 (approved in any line of therapy) | May 16, 2017 (-37 days) [approved only after failure of prior chemotherapy] | Initial Recommendation: Not recommended | 2 |
| nivolumab (Opdivo®) 2nd line | For the treatment of patients with advanced or metastatic NSCLC who progressed on or after chemotherapy | March 4, 2015 | February 26, 2017 (725 days) | Final Recommendation June 3, 2016: Recommended and publicly funded in most provinces | 3 |
| osimertinib (Tagrisso®) 2nd line | For the treatment of patients with locally advanced or metastatic EGFR T790M mutation positive NSCLC who have progressed on or after EGFR tyrosine kinase inhibitor (TKI) therapy | November 13, 2015 | July 5, 2016 (235 days) | Final Recommendation May 4, 2017: Recommended pending cost effectiveness | 3 |
| pembrolizumab (Keytruda®) 2nd line | For the treatment of patients with metastatic NSCLC whose tumours express PD-L1 (as determined by a validated test) and who have disease progression on or after platinum-containing chemotherapy | September 4, 2014 | April 15, 2016 (589 days) | Final Recommendation November 3, 2016: Recommended pending cost effectiveness but not yet funded | 2/3 |
| pembrolizumab (Keytruda®) 1st line | For previously untreated patients with metastatic NSCLC whose tumours express PD-L1 and who do not harbour a sensitizing EGFR mutation or ALK translocation. | October 24, 2016 | July 12, 2017 (261 days) | Final Recommendation August 23, 2017: Recommended, pending cost effectiveness but not yet funded | 3 |
| pemetrexed (Alimta®) 2nd line | For maintenance following first-line pemetrexed and cisplatin for advanced or metastatic non-squamous NSCLC | July 2, 2009 | May 9, 2013 (1407 days) | Final Recommendation November 19, 2013: Recommended, pending cost effectiveness | 3 |
| ramucirumab (Cyramza®) 2nd line | For the treatment of patients with advanced or metastatic NSCLC who progressed on or after platinum-based chemotherapy in combination with docetaxel | April 21, 2014 | July 16, 2015 (451 days) | Closed, not submitted | 3 |

Figure 4 – Date of FDA approval to first provincial coverage

| DRUG Generic name (brand name) | INDICATION | FDA APPROVAL DATE | ADDITIONAL DAYS TO DATE OF COVERAGE BY FIRST PROVINCE | pCODR Status | Phase Data Used |
|---|---|-------------------------|--|---|-----------------------|
| afatinib (Giotrif®) | For the first line treatment of epidermal growth factor receptor (EGFR) mutation positive, advanced Non-Small Cell Lung Cancer (NSCLC) patients | July 12, 2013 | August 19, 2014 (403 days) | Final Recommendation May 2, 2014: Recommended pending cost effectiveness | 3 |
| alectinib (Alecensaro®) 2nd line | As monotherapy for the treatment of patients with ALK positive, locally advanced (not amenable to curative therapy) or metastatic NSCLC who have progressed on or are intolerant to crizotinib until loss of clinical benefit | December 11, 2015 | Not Funded | Final Recommendation: Pending | 3 |
| alectinib (Alecensaro®) 2nd line with CNS | As monotherapy for the treatment of patients with ALK positive, locally advanced or metastatic NSCLC who have progressed on or are intolerant to crizotinib and have CNS metastases | December 11, 2015 | Not Funded | Final Recommendation May 4, 2017: Not recommended | 2 |
| ceritinib (Zykadia®) Resubmission 2nd line | For treatment as monotherapy in patients with ALK positive locally advanced (not amenable to curative therapy) or metastatic NSCLC who have progressed on or who were intolerant to crizotinib | April 29, 2014 | Not Funded | Final Recommendation March 21, 2017: Recommended, pending cost effectiveness | 3 |
| crizotinib (Xalkori®) Resubmission 2nd line | As monotherapy for use in patients with ALK positive advanced (not amenable to curative therapy) or metastatic NSCLC | August 26, 2011 | October 1, 2013 (767 days) | Final Recommendation May 2, 2013: Recommended, pending cost effectiveness | 3 |
| crizotinib (Xalkori®) Resubmission 1st line | As monotherapy for use in patients with ALK positive advanced (not amenable to curative therapy) or metastatic NSCLC | August 26, 2011 | December 1, 2015 (1558 days) | Final Recommendation July 21, 2015: Recommended, pending cost effectiveness | 3 |

ALK = anaplastic lymphoma kinase
CNS = central nervous system

EGFR = epidermal growth factor receptor
NSCLC = non-small cell lung cancer
TKI = tyrosine kinase inhibitor

Continued... Figure 4 – Date of FDA approval to first provincial coverage

| DRUG Generic name (brand name) | INDICATION | FDA APPROVAL DATE | ADDITIONAL DAYS TO DATE OF COVERAGE BY FIRST PROVINCE | pCODR Status | Phase Data Used |
|--|---|-------------------------|--|--|-----------------------|
| dabrafenib (Tafinlar®) + trametinib (Mekinist®) 2nd line | In combination for the treatment of patients with advanced NSCLC with a BRAF V600 mutation and who have been previously treated with chemotherapy | June 22, 2017 | Not Funded | Initial Recommendation August 31, 2017: Not recommended | 2 |
| nivolumab (Opdivo®) 2nd line | For the treatment of patients with advanced or metastatic NSCLC who progressed on or after chemotherapy | March 4, 2015 | March 1, 2017 (728 days) | Final Recommendation June 3, 2016: Recommended and publicly funded in most provinces | 3 |
| osimertinib (Tagrisso®) 2nd line | For the treatment of patients with locally advanced or metastatic EGFR T790M mutation-positive NSCLC who have progressed on or after EGFR tyrosine kinase inhibitor (TKI) therapy | November 13, 2015 | Not Funded | Final Recommendation May 4, 2017: Recommended pending cost effectiveness | 3 |
| pembrolizumab (Keytruda®) 2nd line | For the treatment of patients with metastatic NSCLC whose tumours express PD-L1 (as determined by a validated test) and who have disease progression on or after platinum-containing chemotherapy | September 4, 2014 | Not Funded | Final Recommendation November 3, 2016: Recommended pending cost effectiveness | 2/3 |
| pembrolizumab (Keytruda®) 1st line | For previously untreated patients with metastatic NSCLC whose tumours express PD-L1 and who do not harbor a sensitizing EGFR mutation or ALK translocation. | October 24, 2016 | Not Funded | Final Recommendation August 23, 2017: Recommended pending cost effectiveness | 3 |
| pemetrexed (Alimta®) 2nd line | For maintenance following first-line pemetrexed and cisplatin for advanced or metastatic non-squamous NSCLC | April 2, 2009 | March 3, 2014 (1705 days) | Final Recommendation November 19, 2013: Recommended pending cost effectiveness | 3 |
| ramucirumab (Cyramza®) 2nd line | For the treatment of patients with advanced or metastatic NSCLC who progressed on or after platinum-based chemotherapy in combination with docetaxel | April 21, 2014 | Not Funded | Closed, not submitted | 3 |

ALK = anaplastic lymphoma kinase
CNS = central nervous system

EGFR = epidermal growth factor receptor
NSCLC = non-small cell lung cancer
TKI = tyrosine kinase inhibitor

Figure 5 - Number of days from date of FDA approval to date of provincial coverage

| DRUG Generic name (brand name) | FDA APPROVAL DATE | BC | AB | SK | MB | ON | QC | NS | NB | NL | PEI |
|--|-------------------------|---------------|---------------|---------------|---------------|---------------|---------------|---------------|---------------|---------------|---------------|
| afatinib (Giotrif®) 2nd line | July 12, 2013 | 446 | 445 | 430 | 461 | 403 | 1027 | 535 | 426 | 689 | 1200 |
| alectinib (Alecensaro®) 2nd line | December 11, 2015 | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded |
| alectinib (Alecensaro®) with CNS metastasis | December 11, 2015 | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded |
| ceritinib (Zykadia®) 2nd line | April 29, 2014 | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded |
| crizotinib (Xalkori®) 2nd line | August 26, 2011 | 918 | 797 | 769 | 783 | 767 | 892 | 828 | 805 | 949 | 1711 |
| crizotinib (Xalkori®) 1st line | August 26, 2011 | 1746 | 1763 | 1773 | 1794 | 1749 | 1627 | 1711 | 1879 | 1808 | Not Funded |
| dabrafenib (Tafinlar®) + trametinib (Mekinist®) 2nd line | June 22, 2017 | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded |
| nivolumab (Opdivo®) 2nd line | March 4, 2015 | 728 | 761 | 750 | 740 | 748 | 749 | 759 | 790 | 883 | Not Funded |
| osimertinib (Tagrisso®) 2nd line | November 13, 2015 | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded |
| pembrolizumab (Keytruda®) 2nd line | September 4, 2014 | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded |
| pembrolizumab (Keytruda®) 1st line | October 24, 2016 | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded |
| pemetrexed (Alimta®) 2nd line | July 2, 2009 | 1764 | 1764 | 1705 | 1795 | 1734 | 1917 | 1734 | 1887 | 1734 | 2335 |
| ramucirumab (Cyramza®) 2nd line | April 21, 2014 | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded | Not Funded |

#BEATLUNGANCER – HEATHER HOGAN

Faces of Lung Cancer Patient Story

Meet Heather. She's 58 years old and lives in Woodstock, New Brunswick. A lifelong educator, Heather managed many roles. As a Vice-Principal at the local elementary school and a schoolteacher, Heather is a well-known fixture in the community. In fact, she has taught multiple generations of many families. Needless to say, she is beloved by many.

Most would agree that Heather is someone who always took control, in her profession and at home. Heather was the 'glue' that kept it all together. She was the touchstone. The strong one! However, this all changed when she was diagnosed with lung cancer five years ago.

Heather was no stranger to the disease. Her father was diagnosed many years ago and after a successful surgery, he beat the disease. Although she witnessed the trauma of the disease first-hand, she was not expecting to face the disease herself. Heather was active and healthy. She didn't fit the high-risk profile.

After the tumour was detected, it was stage 3. She underwent a lobectomy to remove the cancer and surrounding lymph nodes. Heather was in a very different position as a lung cancer patient. It completely removed her sense of control. Chemo and radiation were next and although her physical condition was good, she found the emotional strain to be a lot.

Heather had good days where she felt optimistic and empowered. Others were not so great. The mental toll was a constant and Heather battled severe anxiety. As a former educator, Heather was used to being in a school surrounded by lots of people and activity. The solace was tough for her. As a driving force in the family, she was always the first person to

be there for someone. She found it difficult to be on the receiving end of care. Always the caregiver!

Her family became her rock. Heather's husband went to every appointment, spoke to all the physicians – he managed it all. It has been five years since lung cancer changed her life. Now retired, Heather acts as a resource for anyone in her community that is touched by cancer. Her most important lesson ever taught is one of hope and strength!

“No one can prepare you for the emotional and mental anguish that can come with a lung cancer diagnosis. It can wear you down. No matter how strong you think you are. It is okay to admit that you need help. It is okay to lean on someone.”



Heather Hogan
Woodstock,
New Brunswick

#ACCESSTOSPECIALISTS

#NURSENAVIGATION: NEW PILOT SHOWS PROMISE

A unique new program is changing the clinical experience for patients and physicians.

Established in the fall of 2013, the British Columbia Cancer Agency's Nurse Navigator began to show how a strategically placed specialist makes dramatic impacts, for the better. The pilot program at the Vancouver Centre was initiated to streamline the intake and triage process for newly referred lung cancer patients.

The role has many dimensions. The Nurse Navigator is responsible for reviewing patient's referral information and liaising with medical and radiation thoracic oncologists to facilitate additional imaging, expedite requests for molecular testing and conduct symptom screening assessments with patients. Involvement of the Nurse Navigator with triage activities has demonstrated reduced wait times to treatment for patients, increased frequency and availability of molecular testing results at consultation, and improved allocation of time-constrained physician resources.

"The reality is that patients and their families are always grateful to hear from me; we discuss the plan for upcoming appointments and I am able to be a consistent point of contact and provide information to help relieve some of the uncertainty. The sense of fear and anxiety is huge for patients and their families, and this new program really helps alleviate a lot of those concerns."

– **Kelly Zibrik**, Nurse Navigator

Thoracic oncologists at the Vancouver Centre report the integration of the Nurse Navigator has fueled a culture of improved communication via electronic documentation of triage assessment and the treatment plan. The value of having full reports and information at the time of consultation was noted, from both the physicians and the patients. Coordination of referral activities and information by the Nurse Navigator creates a unique, unifying resource that positively impacts appointment and triage planning for the patient, admitting clerks, referring offices, specialist MDs, BCCA physicians and departments.

LCC BELIEVES IT IS NOT TOO LATE TO IDENTIFY A BETTER WAY. IT IS TIME TO FACE FACTS AND WORK FOR REFORM TO MAKE THE NEW FRONTIER OF MEDICINE AVAILABLE TO PATIENTS, FASTER.

“We have clearly demonstrated that the program model works. Since it started, we have worked closely with over 700 patients in the last three years, which is remarkable. Positive clinical impacts are being achieved each and every day, we know time is of the essence for these patients and the improved efficiencies are helping us achieve better patient care.”

– **Dr Cheryl Ho**, MD FRCPC, Medical Oncologist, Clinical Associate Professor, UBC, BC Cancer Agency

The evidence is staring us in the face. Programs designed with intent and implemented effectively will improve a main aspect of the lung cancer journey. The Nurse Navigator pilot program shows us that clinical procedures can be enhanced to improve medical outcomes, but it also creates a human bond. As things currently stand, patients are expected to manage the influx of complex scientific detail, physical symptoms of the disease, along with the intense emotional distress and this is not easy. We need to strive for more programs like this that offer a human touch-point that guides and support the patient.



Kelly Zibrik

Vancouver, British Columbia

#ACCESSTOBESTPRACTICES

QUEBEC'S APPROACH TO LUNG CANCER

In the spirit of progress, identifying best practices at home in Canada and from our international neighbours is one of the most important opportunities to achieve progress, rapidly.

Quebec has a unique model when it comes to diagnosis. Early adoption of new diagnostic techniques is proving to be beneficial.

The province has enabled access to a new diagnostic procedure called endobronchial ultrasound (EBUS). EBUS is a minimally invasive procedure, so patients can have it on an outpatient basis. Technology allows pathologists to sample central lung masses and lymph nodes with the help of ultrasounds, dramatically improving their ability to obtain good biopsies without too much discomfort for the patient. Results can be rapid and within one day a patient can know their diagnosis and stage of the disease and whether surgery is an option.

“Acceptance of diagnostic tests like EBUS have been significant in Quebec and the positive impacts speak for themselves. Governments need to look

at the whole lung cancer picture, not only at treatment alone; diagnostics and screening are also key. Investments must be made for patients and in the long run, we anticipate cost savings.”

- **Dr Nicole Bouchard**, Respiriologist.

Another example from Quebec highlights the collaboration between respirologists and oncologists. Historically, the level of collaboration between these two specialties was limited in Canada. Respirologists managed the screening and diagnosis for the patient but are rarely involved in treatment. Quebec has a very different model that resembles what you see in Europe when it comes to how these physicians work together.

“The patient sees the real power of the unique relationship between respirology and oncology, in Quebec. The partnered approach ensures better disease management with the respirologist who is able to work with the patient to relieve side-effect symptoms, etc. It is a true team effort.”

LCC BELIEVES THAT THERE ARE POSITIVE MILESTONES TO CELEBRATE AND LEARN FROM. TOGETHER WE ARE STRONGER, SMARTER AND READY TO SEE MAJOR CHANGES FOR LUNG CANCER PATIENTS.

A person wearing a white lab coat is holding a colorful ball-and-stick molecular model. The model consists of various colored spheres (red, blue, black, white, purple) connected by grey rods, representing atoms and bonds. The person's face is partially visible in the background, looking towards the camera. The overall scene is set against a light, blurred background.

PART 4

DIAGNOSTIC &
MOLECULAR TESTING

#ACCESSTOTECHNOLOGY TESTING UPDATES

It is a new world in the treatment of lung cancer. The rapid development and approval of innovative treatments has dramatically improved survival rates and quality of life for patients. The advancement of biomarker testing for newly diagnosed patients with advanced non-small cell lung cancer (NSCLC), as well as for patients progressing after treatment with EGFR inhibitors has been a game changer. These are major steps forward inspiring tremendous hope, for patients and their families and the medical community who work so tirelessly to make a difference in the lung cancer story.

Much has changed in the past five years. Our understanding of lung cancer has been expanded and exciting new research is underway demonstrating the power of biomarker testing and the profound impact it has on patient survival and quality of life. Not only can we now identify gene mutations, but also treatment can be targeted for patients that will be effective against these mutations. It is a new world when it comes to testing and we need to start thinking about how best to integrate and standardize approaches to biomarker testing and diagnostics, now.

Currently, the availability of specific tests, equipment and technology are quite different depending on which province you live in or what clinic you visit. The lung cancer community needs to prepare for fast moving technology that will soon make testing much more economical, faster and accessible. It is proven that testing improves treatment success and overall survival and we want to ensure that as new tests and technology become available, we are in a position to quickly adopt and incorporate it into our testing and treatment algorithm.

Establishing guidelines around biomarker testing will be the next step. Ensuring that a standardized approach for all testing is created and infrastructure is designed to evolve with the pace of scientific innovation is paramount. Building on the success biomarker testing has had in lung cancer will only continue to improve the situation and mitigate drastically different prognoses in each province. Lung Cancer Canada has been an active driver of the testing discussion and continues to work with the country's leading specialists to build guidelines and advocate for additional funding.

Some of the research and testing processes being accomplished in British Columbia are a 'mirage' within the mix of an inconsistent provincial framework. Multi-gene analysis panels are now offered across British Columbia as provincial diagnostic tools. This changes the game if you are a patient, centering on a personalized approach to treatment for thousands of eligible cancer patients.

Currently, the OncoPanel and Myeloid Panel are clinical tests that detect multiple different mutations in several genes simultaneously. A first in Canada, the gene testing panel is available province-wide in BC. The work being done by the team of researchers is changing the path for so many Canadians who will encounter a lung diagnosis over their lifetime. Similar programs are running in Alberta and are also making significant progress in the area.

"With cancer, biomarkers are coming fast and furious and our goal is to streamline the process and ensure easy adoption in the future.

Pathology budgets are typically static and don't allow for much flexibility, operational barriers can also be prohibitive and we need to change this in order to fully assess the potential of these new testing methods. We need to advocate for ourselves."

- **Dr Quincy Chu**, MD, FRCPC, Associate Professor, Division of Medical Oncology Department of Oncology, Cross Cancer Institute, University of Alberta.

The core dynamics of the various programs consist of a biopsy of suspected lung cancer tumour and submission of the DNA for testing. Multiple single gene sequencing tests are integrated onto a single Next-Generation sequencing panel, resulting in rapid diagnoses. Previous methods tested each gene separately and the time required was considerable. The process then takes two to three weeks for an accurate picture of how best to target

treatment for the patient. These are game-changing steps forward in the battle against lung cancer.

Health economic studies show that the panel-testing program is a cost effective way to improve cancer outcomes.^{xv} The gene mutations are being selected because they are the most clinically relevant for known publicly funded treatment plans or ongoing clinical trials. If tests were expanded to include other mutations, irrespective of what is publicly funded, the number of saved lives could be significant.

Calls should be loud to champion increased funding of genomic testing. It is a proven advancement, evolving at accelerated speed. The example in BC needs to be closely evaluated and studied. This is the future of cancer diagnosis and treatment action and something that shines with hope for a beleaguered patient community.

LUNG CANCER CANADA BELIEVES THAT CALLS SHOULD BE LOUD TO CHAMPION INCREASED FUNDING OF GENOMIC TESTING.



Dr Quincy Chu
Edmonton, Alberta

#BEATLUNGCANCER – LORNE COCHRANE

Faces of Lung Cancer Patient Story

Meet Lorne. He is 58 years old and no stranger to the ravages of lung cancer. The disease claimed the life of so many who were close to him. His grandfather. His mother. Two of his aunts. It was the stage-1 diagnosis of his twin brother and death of his mother in 2012 that propelled Lorne to get screened.

Despite having no symptoms, Lung cancer was staring Lorne directly in the face and something was telling him that he needed to look into it. The disease spread from several tumours in both lungs, to the adrenal gland, kidney, and pancreas.

Radiation or surgeries were not options. Palliative chemotherapy was the course of treatment and Lorne was given 12-13 months to live. This was a shock to Lorne, his wife and children. He was in good shape and felt fine. How could he only have a year of life left? Lorne was always optimistic and his perspective didn't change in the face of Canada's number one cancer killer.

Lorne's wife was not ready to accept the news. She was not ready to lose her husband, her

touchstone, and her best friend. Maryann was driven to do everything in her power to help her husband and began to research new treatments and clinical trials that if anything, could give Lorne more time. After the chemo quit working, Mary and Lorne went and discussed with their oncologist the possibility of other treatments such as clinical trial drugs. Lorne said, "I'm young and still feel healthy, why don't you try something on me now instead of waiting until I'm on death's door step. If it will benefit others and maybe myself, then I'm willing to be a test pilot. After a few weeks, Lorne's oncologist called him and said that a trial had come available and asked if he would like to participate and Lorne said "yes!" Without hesitation.

After working with his oncologist to complete the required tests, he was enrolled in the trial and began the treatment. His side effects were minimal. After 4 weeks the phlegm cleared up, a positive sign. After 9 weeks on treatment, the medical team noticed something. Lorne's tumours showed a major reduction in size. This was incredibly promising for Lorne, his family and the researchers following his journey.

LCC BELIEVES THE FUTURE OF TARGETED TESTING IS NOW. INCREASED INVESTMENT WILL FUEL ADVANCING SCIENCE AND DIRECTLY IMPACT THOSE STARING LUNG CANCER IN THE FACE.

Eventually, the tumours were un-measurable and the prognosis he had initially received disappeared. It was a remarkable response from a new approach to treatment that would change the way the medical community looked at treating lung cancer. Lorne's story highlights the importance of persistence and hope. Science and innovation would change life for him and his family. Lorne remarks, "Science and research are how I spell HOPE". Lorne's twin brother Lloyd was not fortunate enough to be on the same treatment and passed away in November 2016 due to complications from his Lung Cancer.

It has been 5 years and 7 months since his diagnosis and Lorne credits his wife, his doctor and all of the researchers for saving his life. He continues to undergo routine screening and considers this the 'new normal'. Lorne and his family urge patients to never give up, lung cancer can be beaten and he is living proof.

"A lung cancer diagnosis can be paralyzing. You need an ally who can go along the journey with you, no one person can battle lung cancer alone."



Lorne Cochrane
Atmore, Alberta



LEADERS

CONCLUSION

#ACCESSREFORM

MOVING IN THE RIGHT DIRECTION

The Canadian lung cancer story is one riddled with obstacles. Monumental challenges characterize the disease and give the illusion of defeat. Undeterred by the enormity of the situation, the lung cancer community maintains hope. Research that pushes the boundaries has yielded targeted treatment solutions, advanced screening protocols, and state-of-the art biomarker tests have become the hallmark of the new lung cancer narrative.

We need to keep it simple. A few critical elements will fundamentally change everything.

The past year saw significant steps to improve the lives of patients and we are thankful for this. These victories are important to celebrate, but we must always push the envelope. We fight for the faces of countless loved ones.

Standing alongside our partners living with the disease, those in clinical practice, government and research, we want to change this story. Early intervention. Comprehensive screening. Access to targeted treatment. More survivors! We act on behalf of patients for patients. Driving the lung cancer agenda through a sustained dialogue will enable change.

LUNG CANCER CANADA WANTS 2017 TO BE THE PIVOT YEAR FOR CANADA'S LARGEST CANCER KILLER. WE HAVE THE EVIDENCE. WE KNOW THAT EARLY DETECTION SAVES LIVES AND OPTIMIZES HEALTH SERVICES. WE KNOW THAT TREATMENTS ARE RAPIDLY EVOLVING AND HAVING PROFOUND IMPACTS ON THE PROGRESSION OF THE DISEASE. OUR FOCUS NOW NEEDS TO SHIFT TO ACCESS AND WE WILL ADVOCATE ON BEHALF OF ALL PATIENTS TO IMPROVE DRUG DELIVERY AND DIAGNOSTICS IN CANADA. TOGETHER WE ARE STRONG! TOGETHER, CHANGE IS POSSIBLE!



PARTNERS

WHO WE ARE

#LCC LUNG CANCER CANADA

Lung Cancer Canada is a national charitable organization that serves as **Canada's leading resource for lung cancer education, patient support, research and advocacy**. Based in Toronto, Ontario, Lung Cancer Canada has a wide reach that includes both regional and pan-Canadian initiatives. Lung Cancer Canada is a member of the **Global Lung Cancer Coalition** and is the **only organization in Canada focused exclusively on lung cancer**.

Lung Cancer Canada's mission is four-fold: **1) to increase public awareness of lung cancer**; **2) to support and advocate** for lung cancer patients and their families; **3) to provide educational resources** to patients, family members, healthcare professionals, and the general public; and **4) to raise funds** in support of **promising research opportunities**.

Lung Cancer Canada also offers a **variety of resources** to educate and support patients and their families. These include: **1) our website**, which serves as a trustworthy and timely source of lung cancer information and news; **2) our newsletter**, Lung Cancer Connection, which explores topics of interest to the entire lung cancer community; **3) our Resource Library**, which allows patients and their families to access specialized information; and **4) our social media presence**, as well as the **discussion forums** and **patient stories** on our website, which offer lung cancer patients and families the opportunity to **connect and offer support to one another**.



**LUNG
CANCER
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AWARENESS. SUPPORT. EDUCATION.

WWW.LUNGCANCERCANADA.CA

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- ^{xvii} Lung Cancer Canada
- ^{xviii} Decreasing Smoking but Increasing Stigma? Anti-tobacco Campaigns, Public Health, and Cancer Care Kristen E. Riley, PhD, Michael R. Ulrich, JD, MPH, Heidi A. Hamann, PhD, and Jamie S. Ostroff, PhD
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