THE FACES OF LUNG CANCER REPORT

RESEARCH AND ANALYSIS OF THE LUNG CANCER 'WAITING GAME'

LUNG CANCER CANADA

AWARENESS. SUPPORT. EDUCATION.

2016

THE FACES OF LUNG CANCER REPORT

NOVEMBER 2016

#HOPEUNITES

A MESSAGE FROM LUNG CANCER PATIENTS – 2016 LUNG CANCER CANADA REPORT

FOREWARD

LUNG CANCER PATIENTS AND FAMILIES DESERVE TO BE SUPPORTED

We live in a world where everything is happening faster than ever before. Meanwhile patients with Canada's number one cancer killer are playing a **waiting game to survive**! Although lung cancer kills more people than breast, prostate and colon cancer combined, it carries with it a heavy sense of stigma and falls **far behind other cancers** in terms of **research**, **patient support** and **timely access** to **new and emerging therapies**. This disparity can have a profound impact on quality of life and overall survival.

As the collective patient voice, Lung Cancer Canada has a **front row seat to these disparities** – we feel the trauma of a diagnosis in our fight, and we do our best to navigate a complicated system that has not kept pace with our "real-time" reality. Each day is a gift and, despite a long list of inequities, as a community of patients, caregivers, families and supporters, we remain hopeful and determined – **lung cancer will not be forgotten!** Driven by our collective will to live, we will advocate for **improved access to new and effective therapies**, while championing a more efficient process for the **approval and funding of critical lung cancer treatments**. It is never too late to drive change. We remain hopeful, focused and strong in our pursuit to address the stigma around lung cancer and to increase literacy about this disease, which killed almost 21,000 Canadians, just last year.

We urge everyone to **listen**, **empathize** and **act** to lessen the burden of lung cancer in Canada. **The social and economic toll being placed on the system is unsustainable and will soon reach an apex.** Improved support, research and faster access to innovative therapies will improve the lives of patients and their caregivers. We want to keep pace with the speed of innovation. Lung cancer is a killer that leaves patients without time to wait. **Join the lung cancer community** and help us make changes that can **dramatically improve lives and outcomes**.

– Canadian Lung Cancer Patients, Caregivers, Families and Supporters

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INTRODUCTION

Joseph Spampinato and family from
Upper Tantallon, Nova Scotia

#REALITYCHECK – REAL-TIME OVERVIEW

#Hope-is-Here for Canadian lung cancer patients. Lung cancer still remains among the **most commonly diagnosed of all cancers**, but thankfully, **awareness is increasing**. The narrative of lung cancer appears to be propelled in a **positive, more compassionate direction**. Each year Lung Cancer Canada makes progress in its quest to increase lung cancer literacy in Canada.

Innovation and research are helping to **drive solutions that offer hope to patients and their families**. Screening and acceptance of screening can help with early detection, which leads to people living longer. In addition, in just the last five years, Canadian patients have seen a number of new treatments become available. In fact, since 2011, Health Canada has approved **seven new lung cancer drugs** (afatinib, ceritinib, crizotinib, nivolumab, osimertinib, pembrolizumab, and pemetrexed). However, regrettably, **approval times, cost and delayed public funding** of these new drugs are barriers that **prevent timely access**.

Today, we are at a critical stage in the battle against lung cancer, where **opportunities for more expansive screening** and an **urgent need for improved access** to new and emerging medicines are all on the table. If these are not addressed in a timely manner, the consequences could be dramatic.

The lung cancer community faces the realities of the disease every day. They know the **20,800** Canadians who will die from the disease in 2016 and the **28,400** who received a diagnosis[1] – these people are the **FACES OF LUNG CANCER**.

"There is an immediate shock when you are first diagnosed with cancer, it acts almost like a fog and you typically don't remember much after your doctor tells you it is lung cancer," says Ian McAlpine. "My wife was with me from the moment my doctor uttered the words lung cancer and she remains by my side as I continue to control the disease, it is important for everyone involved to stay strong and carry on."

Lung Cancer Canada applauds all of the hard work that has been done to improve the opportunities for lung cancer patients and their families. However, we have just scratched the surface and there is **still so much to do**. Addressing issues of **awareness**, **support**, **education**, **research** and **access** will be a mainstay in our fight while we brace ourselves to tackle emerging issues such as the little-known rising incidence rates of lung cancer among Canadian women.

INNOVATION AND RESEARCH ARE HELPING TO DRIVE SOLUTIONS THAT OFFER HOPE TO PATIENTS AND THEIR FAMILIES.

PART 2
LUNG CANCER IN CANADA

#SCREENINGSAVES – 2016 SCREENING UPDATE

It has been well documented that **the earlier lung cancer is diagnosed, the better the opportunity for curative treatment**. In fact, lung cancer patients can look to affirming results from national screening programs with improved survival rates in cancers like breast, colorectal and cervix. Unfortunately, the current situation for lung cancer patients is quite different and dire. With **no national lung cancer screening program currently in place**, almost half (48%) of lung cancer diagnoses are made when the cancer is **already at stage 4**, the most advanced and incurable stage, meaning it has already spread outside of the lung. A further 27% of patients are diagnosed at stage 3, and of these, only one-quarter may ultimately be cured.[2]

#Hope-is-Here. Just this year, there was a major achievement in the fight against lung cancer when a **landmark recommendation for screening** was announced. Published in the March 2016 issue of the Canadian Medical Association Journal (CMAJ), the Canadian Task Force on Preventive Health Care released a new guideline recommending **annual lung cancer screening** in high-risk adults ages 55-74[3], using the newest screening method, **low-dose computed tomography (LDCT)** screening. This method offers much greater promise by yielding a more comprehensive view of the lung tissue and minimizing a patient's radiation exposure to only 20% of the radiation from a normal CT scan. As an example of the potential impact these guidelines can have, a similar task force in the United States in 2013 issued guidelines for slightly more expansive screening, but that nevertheless targeted high-risk individuals. The results from the implementation of these particular screening guidelines have shown a **20% drop in lung cancer mortality across the United States**.[4] Based on data extrapolated from the National Lung Screening Trial in the United States, a similar program in Canada could be expected to **save more than 1,200 Canadian lives per year**[5].

According to the Pan-Canadian Early Detection of Lung Cancer Study,[6] screening has the potential to **save both lives and money**. The average cost to screen individuals at high risk for developing lung cancer using LDCT was $453 for the initial 18 months following a baseline scan. If a patient can receive curative surgery, the average per person

THE EARLIER LUNG CANCER IS DIAGNOSED, THE BETTER THE OPPORTUNITY FOR CURATIVE TREATMENT... SCREENING HAS THE POTENTIAL TO SAVE BOTH LIVES AND MONEY.

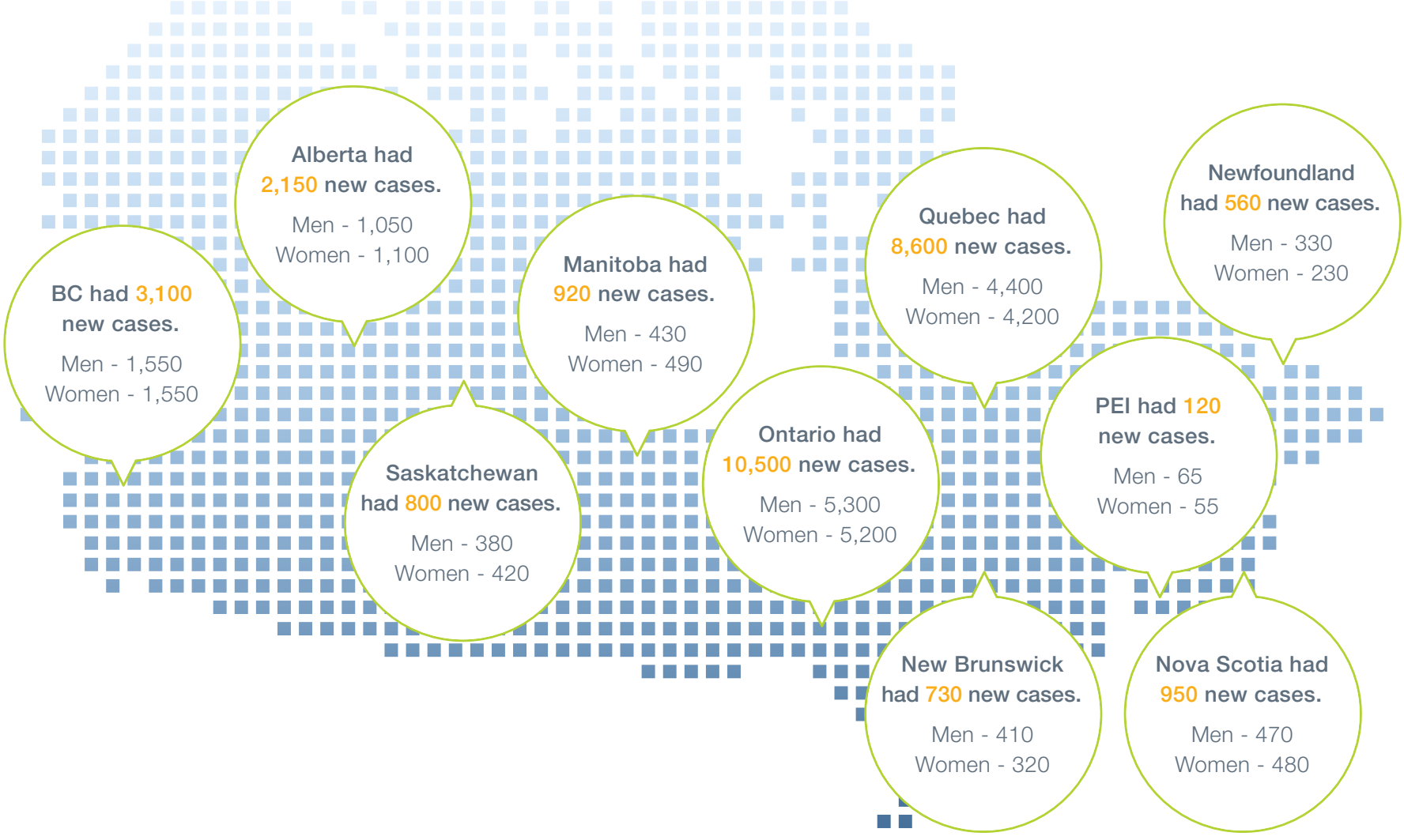
treatment cost was $33,344 over two years. This is significantly lower than the average per person treatment cost of $47,792 for advanced-stage lung cancer with chemotherapy, radiotherapy or supportive care alone.[7] This **economic benefit** is in addition to the **life saved** and the ripple of survival that further strengthens families, loved ones and their communities.

Although there is still work to be done, provinces are taking steps to examine how screening programs can be integrated into provincial systems. British Columbia, Alberta and Ontario may be furthest ahead with ongoing pilot projects (British Columbia and Alberta) or pilots scheduled to begin (Ontario). Other provinces are working with their ministries of health to examine screening. The Canadian Partnership Against Cancer has organized a Pan-Canadian Lung Cancer Screening Network (PLCSN), a group that aims to leverage expertise and evidence-based recommendations to support policy and best practices in lung cancer screening. The PLCSN's Lung Cancer Screening Framework for Canada addresses key considerations for the delivery of lung cancer screening, and highlights key components of an organized population screening program. While the Framework provides guidance for organizations considering the implementation of organized lung cancer screening, it also includes key considerations relevant to clinicians contemplating referral of their patients for lung cancer screening to maximize benefits and minimize potential harms.

LUNG CANCER CANADA BELIEVES THAT THE NEW CANADIAN GUIDELINES HOLD SIGNIFICANT IMPORTANCE FOR THE FUTURE OF LUNG CANCER IN CANADA AND WE ARE ENCOURAGED BY THE PROSPECTIVE IMPACT IT MAY HAVE ON LUNG CANCER DIAGNOSES ACROSS THE COUNTRY. WE URGE FEDERAL AND PROVINCIAL DECISION-MAKERS TO EXPEDITE THE PROCESS AND ADOPT A NATIONAL SCREENING FRAMEWORK.

#COASTTOCOAST – LUNG CANCER ACROSS CANADA

Figure 1 - New lung cancer diagnoses in 2016[8]



#LUNGCANCER411 – LUNG CANCER FACTS

Statistics illustrate the number of patients diagnosed and living with a disease. Lung cancer statistics can be shocking at first glance, but they simply **cannot convey the human impact of lung cancer**. **Every week** countless numbers of family and friends say their goodbyes to the more than **400 Canadians** who die from lung cancer, more than any other type of cancer – and **more than the other common cancers**, breast cancer, colorectal cancer and prostate cancer, **combined**.[9]

1 in 13 Canadians will develop lung cancer during his/her lifetime.[10]

Canada has a higher mortality average than other Organization for Economic Co-operation and Development (OECD) peer countries.[11]

Smoking causes most lung cancers. However, about **half** of patients who are diagnosed have either **never smoked** (15%) or are **former smokers** (35%).

The majority of lung cancers are **diagnosed in late stages**, due in part to lack of effective screening procedures.

Lung cancer patients and their family members are often **stigmatized by a widespread prejudice about smoking**, and many feel isolated and hesitant to tell others about their diagnosis.

Lung cancer receives l**ittle public or media attention**. This is due, in part, to a small community of survivors who can bring a voice and attention to lung cancer issues.

#LUNGCANCHER – NEW RESEARCH: CANADIAN WOMEN DISADVANTAGED

A recent Canadian Institute for Health Information (CIHI) report looked at a 50-year period between 1960 and 2010 and compared Canadian performance in lung cancer against 17 other countries. Their findings showed **Canadian women are losing more years of potential life from lung cancer than women in most other peer countries**.[12] In addition, since 1960, Canadian women have continuously moved toward last place and are at risk of having the **highest number of Potential Years of Life Lost (PYLL)** from lung cancer than any other peer country.[13]

These findings add to the growing amount of evidence that lung cancer is a **women's health issue**. Another CIHI report released in 2013 showed that Canada had the third highest female lung cancer death rate out of 33 other peer countries studied.[14] Over the last 30 years, lung cancer incidence has increased in young women, while it has decreased in young men (ages 20 to 44).[15] **Lung cancer kills more women than any other cancer**, and specifically kills more women than **breast cancer**, **uterine cancer**, **cervical cancer** and **ovarian cancer**, combined.[16] The evidence is clear. Canadian women are falling behind in the battle against lung cancer.

Lung Cancer Canada believes that Canada must develop strategies to **address these findings** in order to **decrease both the lung cancer incidence and mortality rates in Canadian women**.

"I thought I was protecting my health by not smoking, eating healthy and maintaining an active lifestyle, lung cancer was not even on my radar as a young woman," says Elizabeth Dessureault a lung cancer survivor in Ottawa, Ontario. "I was pregnant with my first child and quickly recognized my diagnosis was real and I needed to remain hopeful, yet determined to beat my lung cancer."

CANADIAN WOMEN ARE LOSING MORE YEARS OF POTENTIAL LIFE FROM LUNG CANCER THAN WOMEN IN MOST OTHER PEER COUNTRIES.

Jill Hamer-Wilson and family from Ottawa, Ontario

#STOPCANCERSHAMING – LUNG CANCER & STIGMA

LUNG CANCER CANADA RE-EMPHASIZES THAT NO ONE DESERVES LUNG CANCER AND BELIEVES WE CAN DO BETTER! LUNG CANCER IS OUR COUNTRY'S BIGGEST CANCER KILLER – WE MUST IMPROVE THE SITUATION FOR PATIENTS AND THEIR FAMILIES.

The association between lung cancer and smoking puts the additional **weight of stigma** on top of the already heavy burden brought on by a lung cancer diagnosis. Smoking is a cause of lung cancer, but it should not be used as an excuse to blame or withhold empathy. **"Did you smoke?" should not be a substitute for "How are you?"** The truth is, if you have lungs, you can get lung cancer. In fact, as many as **15%** of lung cancer patients are life-long non-smokers, and **50%** of patients diagnosed with lung cancer have quit before the time of diagnosis.[17]

This stigma though is a **persistent feature in the lung cancer reality**. Survey results from our *2015 Faces of Lung Cancer Report* indicate that caregivers feel the stigma more acutely than patients. **38%** percent of caregivers felt that they had to advocate harder for their loved ones. Research also shows that the stigma **holds patients back** from telling family and friends about their diagnosis and causes them **reluctance to seek support**.[18] Lung cancer patients face the overwhelming reality of the disease, but also a **secondary fight** to break the stigma. The community of caregivers and patients maintain efforts to raise awareness, improve understanding and empathy, while increasing research and treatment resources.

"When I tell people that my dad died from lung cancer, I can still **see the stigma that is attached to the disease in their facial expressions**," says Christina Amaral, daughter of Ed who died of lung cancer. "I always feel the need to somehow justify that yes, my dad had lung cancer but no he didn't smoke. It feels like a race to get out as much information as I possibly can to try and prevent them from formulating a negative opinion about the type of lifestyle he must have had and I am determined to change this."

Christina Amaral
of Toronto, Ontario

ELIZABETH DESSUREAULT OF OTTAWA, ONTARIO

Elizabeth was four months pregnant at the time of her lung cancer diagnosis. Her only early symptom was shortness of breath and she assumed this was a result of the pregnancy. At home one day, Elizabeth started to cough-up blood - this was the catalyst that sparked her to seek medical help.

As a young and healthy woman who never smoked, lung cancer was not on Elizabeth's radar, not even something in the realm of possibilities. She was first misdiagnosed with pneumonia and it wasn't until a second visit to the hospital that she received a diagnosis of lung cancer. Aside from the shock and devastation that the diagnosis brings, Elizabeth was also left with a dismal survival prognosis, for herself and the baby. To compound the devastation, she was also let go from her job as a teacher and left without insurance.

Despite a grim situation, Elizabeth was determined to live. Living with her husband in Alberta at the time, the two decided to move back home to Ontario, so they could be close to family and friends. Elizabeth never gave up hope and every night she committed to reading one lung cancer survivor story, this is what kept her optimistic and gave her the strength to face another day.

Back in Ontario, Elizabeth sought the opinion of another medical oncologist and this is where she began the fight for her life, and her unborn child. After a promising appointment, she went ahead with a course of chemotherapy that was safe for the baby. She was able to shrink the size of the tumour and give birth to a healthy son, two months prematurely.

After the birth of her son, Elizabeth took the situation into her own hands and had a biomarker test done in the United States. She was able to identify a targeted treatment that would inevitably shrink the tumour and allow her to participate in a new clinical trial that reduced the tumour so significantly that she would be eligible for a lobectomy. After a yearlong fight for her life, Elizabeth was told she had no evidence of the disease.

Elizabeth shares back the strength that she received from all the hope-filled survivor stories with a blog (fromlizzieslungs.com), dedicated to helping those who are managing a lung cancer diagnosis.

Elizabeth Dessureault and son, Jack
of Ottawa, Ontario

PART 3
LUNG CANCER RESEARCH TRENDS

#GLOBALRESEARCHUPDATE – THE "INVISIBLE" CANCER

The "invisibility" of lung cancer is a sentiment that is prevalent both in Canada and on a much larger global scale. Lung Cancer Canada belongs to a coalition comprised of patient groups from around the world, known as the **Global Lung Cancer Coalition (GLCC)**. The GLCC wanted to take a deeper look at how exactly lung cancer compares to other cancers and initiated a study to closely examine the situation with input from over 24 countries, including Canada.

As clearly stated by the GLCC, **research is essential** in order to **drive improvements in cancer prevention, screening, diagnosis and treatments**.[19] Given the global impact of lung cancer (over 1.6 million annual deaths)[20] concerns have been voiced about the adequacy of efforts and progress being made in lung cancer research. To assess the situation, the Institute of Cancer Policy was engaged to **examine the state of global lung cancer research** to better understand the types of research activities in progress, to identify the leaders of these efforts, and to highlight areas that need additional research investment. The following 24 countries were evaluated, as they are where the majority of lung cancer research occurs: Australia, Austria, Belgium, Brazil, Canada, China (People's Republic of), Denmark, France, Germany, Greece, India, Italy, Japan, Netherlands, Norway, Poland, Taiwan, Turkey, South Korea, Spain, Sweden, Switzerland, United Kingdom and the USA.[21]

A core objective of the analysis was to **identify if research outputs have changed over time**, as well as the specific **area of focus** and **how close it is to lung cancer patients**. This level of detail from a country-specific perspective will be important in guiding policy discussions and helping to pinpoint where improvements can be made.

Worldwide, the **number of papers** published on lung cancer has more than doubled from 2,157 in 2004 to **4,845** in 2013.[22] Canada ranked ninth out of the 24 countries for published papers on lung cancer research (see Figures 3 and 4).

When evaluating the types of lung cancer research receiving the most attention, the areas of **medicines** and **biomarkers** accounted for the highest proportion of research with 31.5% (1,238 papers). Palliative and supportive care and quality of life issues were the least researched category, accounting for just 0.7% and 0.3% of papers, respectively (a combined total of just 42 papers in 2013). This despite the fact that the **majority of patients will require supportive care at some point in their care path** given the poor survival rates with lung cancer.

Although progress has been made, there has only been a small increase in the proportion of global cancer research that is dedicated to lung cancer – from 4.4% in 2004 to **5.6%** in 2013. In Canada, although lung cancer accounts for **27%** of all

LUNG CANCER CANADA BELIEVES THAT RESEARCH INVESTMENT MUST INCREASE TO MATCH THE SCOPE OF THE DISEASE. RESEARCH MUST DIVERSIFY TO COVER THE ENTIRE LUNG CANCER JOURNEY, INCLUDING SUPPORTIVE CARE.

cancer fatalities, it receives **less than 7% of the research funding dedicated to cancer**.

Still, **#Hope-is-Here** and visible progress is being made. Imagine what could be accomplished if research funding were proportional to the needs of the disease!

"Lung cancer is so much more than how many people are diagnosed and how many people die, it is a complex disease with social, economic and human impacts that have incredible reach and this needs to be continually examined," says Miriam David of North York, Ontario, lung cancer survivor.

Figure 2 – Countries ranked by volume of papers

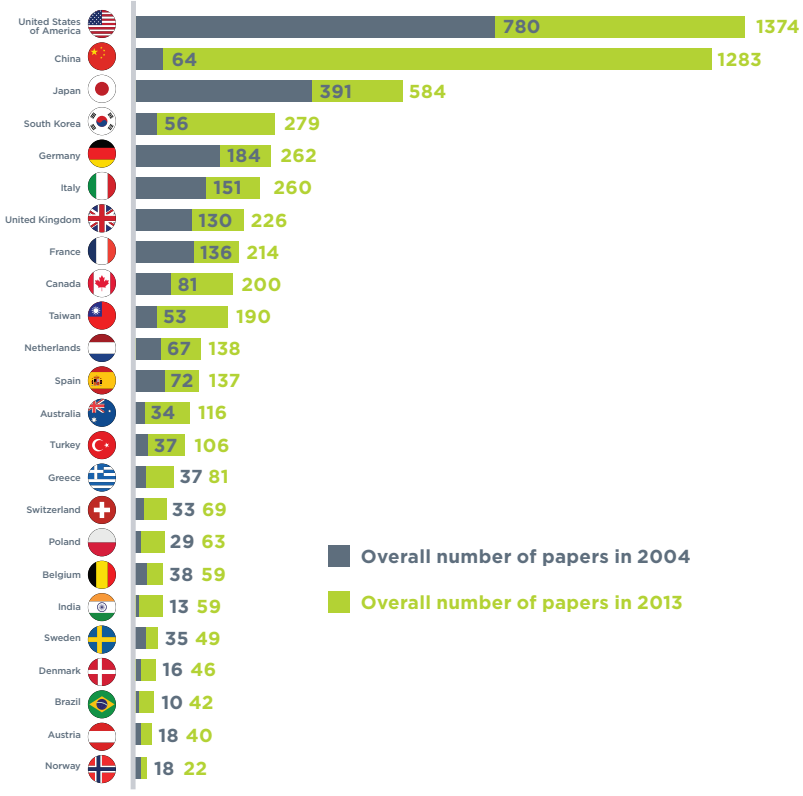


Figure 3 – Proportion of research output on breast cancer vs. lung cancer vs. colorectal cancer

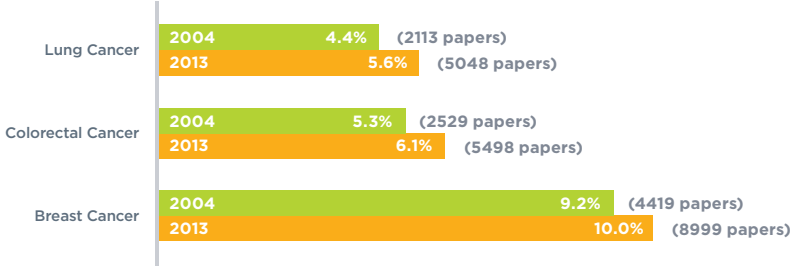
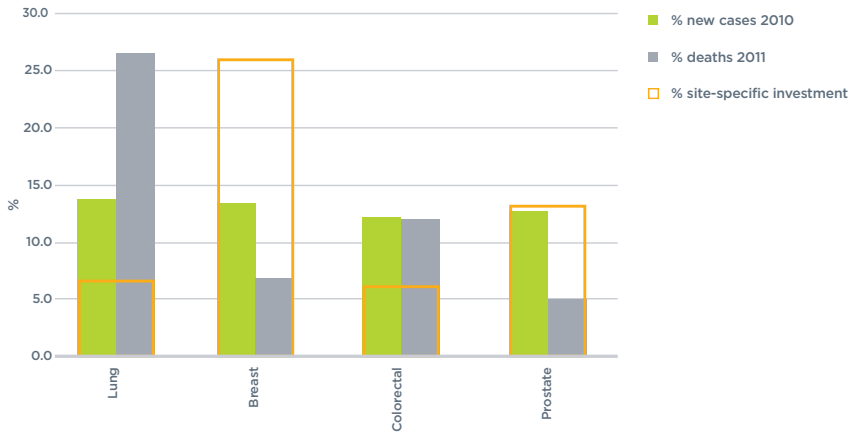


Figure 4 – Proportion of research investment in Canada for select cancers relative to the distribution of new cases and cancer deaths



MIRIAM DAVID OF NORTH YORK, ONTARIO

As a teacher, Miriam shared her life with students and she hopes her lung cancer journey will inform a whole new audience of survivors. After retiring from a long teaching career in 2010, Miriam did not expect such devastating news in 2011 with a lung cancer diagnosis.

Miriam David and Joel Shapiro of North York, Ontario

Miriam was determined, and her journey places a spotlight on the hurdles and great lengths a patient has to overcome to be a survivor in Canada. Everything appeared to be on the right track, she was receiving the 'gold-standard' of chemotherapy and remained hopeful. Unfortunately, the chemotherapy treatments were unsuccessful and the tumours continued to grow in her lung.

Like so many patients before her, Miriam had to take matters into her own hands and fight for her life. This meant looking at biomarker testing in the United States to determine which mutation of lung cancer she had, and which of the newly targeted treatments might work if she had a mutation for which there was a targeted drug. She was successful, received the right tests and had the marker she was looking for. Unfortunately, the right drug to treat Miriam's mutation was not approved or available in Canada at that time, but Miriam was not about to take no for an answer. Miriam purchased her initial dose of the drug through her physician in the US while her Canadian doctor began to work with Health Canada and the pharmaceutical company to get her the required drug on compassionate grounds in Canada. This route was successful and some months later the drug was finally approved for treatment in Canada.

This targeted treatment worked well, allowing Miriam to see her daughter complete her course of study to become a Clinical Psychologist, attend her son's wedding and experience the birth of her first grandson. After about fourteen months, she needed to examine a new option as the drug had stopped working. A new clinical trial enrolled Miriam and again she saw success with treatment, this time for a period of three years. While the drug continued to control the cancer in her lung, brain metastases were now detected.

Again, Miriam looked to the US where cancer drugs are expedited through approvals and made available to patients much faster than in Canada. Working with her US physician, she was able to buy two months supply of a next generation drug recommended by her Canadian physician at a cost of $36,000 Canadian dollars. As of October 2016, this drug has been approved for treatment and sale in Canada. She is currently working with her doctor and the pharmaceutical company to receive this drug on companionate grounds while her insurance company reviews her request to have it included as an approved drug for reimbursement.
She is currently on this treatment and is responding positively.

Miriam teaches a lesson of strength, and the importance of knowing what treatment options exist, and how to get them. Although Miriam is thankful for her ability to access expensive treatments, her message is loud and clear - no matter what your economic status, you should have options that can save your life, too!

PART 4
ACCESSING LUNG CANCER TREATMENTS IN CANADA

#TREATMENTINCANADA – A NATIONAL OUTCRY FOR A FAIR FIGHT

The last decade has seen significant advancements that have **changed the way a lung cancer diagnosis is treated**. Previously, treatment options were limited primarily to chemotherapy whose side effects would often diminish the quality of life a patient still had left. **#Hope-is-Here** as treatments with **improved survival rates** and **fewer side effects** have been approved, but our healthcare system has not been prepared for them. **Limited access to new and emerging medicines has become the outcry of the cancer community**. With high rates of lung cancer and a poor survival prognosis, this is an area that **needs the attention of decision-makers now**.

The wave of new **immunotherapy drugs** and **targeted treatments** has seriously changed the game when it comes to treating lung cancer. These types of innovation come at a significant cost. With cancer control budgets already under pressure, the hope that these and other new treatments embody will dangle just out of reach for patients unless proper attention is given and action is taken.

When examined even closer, patients are not only being **denied potentially effective new medicines**, they must manage a **confusing "patchwork" of different provincial guidelines and drug listings**. In last year's *Faces of Lung Cancer Report*, the fact that lung cancer is a "postal code" disease was discussed. Despite this harsh fact, we remain hopeful for the potential for progress and change. We are committed to working for an improved system, one that is admired by other nations and that gives patients a fair fight against their disease.

"Although the diagnosis was devastating to me, it was not going to take my hope," says Ian McAlpine. "The treatment that would be most effective for me was not available in British Columbia and that meant travelling to Ontario to receive it. The added expense and energy was almost too much to handle and made my journey that much harder."

LIMITED ACCESS TO NEW AND EMERGING MEDICINES HAS BECOME THE OUTCRY OF THE CANCER COMMUNITY.

#LUNGCANCERWAITINGGAME – #HOPE-IS-HERE BUT PATIENTS ARE WAITING

THE FRASER INSTITUTE REPORT INDICATES THAT THE TIME TO REVIEW EACH OF THE DRUGS THEY ANALYZED IS 1.5 TO 4.5 TIMES LONGER IN CANADA THAN IN THE US.

Canada is progressive in many ways, but we may be falling behind when it comes to health policy and health system infrastructure.

An analysis from the Fraser Institute entitled *Potential Impact of Delayed Access to Five Oncology Drugs in Canada*, showed that **of 33 new oncology drugs** developed over an eight-year period, **only 24 received approval in Canada**, whereas 30 were approved in the US.[23] Not only do Canadian patients have **fewer options** than their US peers, but their **wait times** to access these drugs are also almost double (356 days compared with 182 in the US) for the same 24 cancer drugs.[24]

It is this delay that is examined in our *2016 Faces of Lung Cancer Report*. Lung Cancer Canada looked at the most recent eight lung cancer treatments **approved by Health Canada** (as of September 15, 2016), **investigating the time it takes for them to become routinely available for patients**. We looked at the time to provincial public funding from US Food and Drug Administration (FDA) approval of that treatment. 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. To clinicians, patients and families, the wait time may be longer.

On average, the eight indications we looked at received Health Canada approval (Notice of Compliance [NOC] or Notice of Conditional Compliance [NOCc]) **440 days after FDA approval** (see Figure 6).[25] First-line afatinib received Health Canada approval the fastest at 112 days after FDA approval, while maintenance pemetrexed chemotherapy took the longest at 1407 days. While it is true that Health Canada received the file for approval from manufacturers after the FDA in the pemetrexed case, significant delays still exist. The Fraser Institute report indicates that the time to review each of the drugs they analyzed is **1.5 to 4.5 times longer in Canada than in the US**.[26]

Health Canada approval does not mean easy access to the drug for patients without private insurance or deep pockets. After NOC/NOCc, the waiting game continues for **provincial coverage**. For the drugs examined in the Fraser Institute report, the timeline for public funding was between **56 and 412 days after receiving marketing approval from**

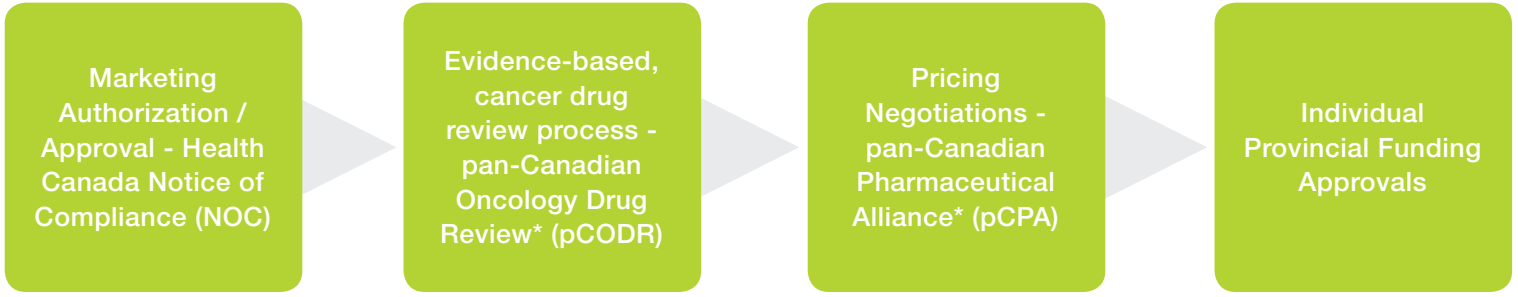
Health Canada.[27] For the eight treatments we examined, the best-case scenario was still **well over a year from FDA approval to coverage by the first province** (see Figure 7).[28] A 2016 Innovative Medicines Canada report showed that of the **27 cancer drugs that were approved in Canada** between January 1, 2010 and December 31, 2014,[29] **only 59% were covered by public drug plans across all provinces**. This ranked Canada **17th** amongst the 20 OECD countries that were used for comparison.

In our analysis, the situation is even more alarming. The sad news is that **provincial coverage is not universal** – some provinces have denied funding to the new lung cancer drugs, while others are making patients wait while decisions are pending (see Figure 8)

The **ceritinib** case is an example of how lung cancer is a waiting game. This drug was approved by Health Canada on April 7, 2015 despite being **approved by the FDA nearly a year earlier** on April 29, 2014. There is still no provincial public coverage for this treatment. As a result, patients who could potentially benefit from this treatment have limited access and are **losing time and their lives as they wait**.

Delays can result at any stage of Canada's multi-step approval and funding process. Essentially, our system follows a four-step process and the **federal and provincial systems act as hurdles** in the race to get new treatments to patients.

Figure 5 – Canada's drug approval and funding process



*In Quebec, the Institut national d'excellence en santé et en services sociaux (INESSS) evaluates medicines and makes recommendations to the Ministry of Health. INESSS is composed of physicians (general practitioners and specialists), pharmacists, a pharmacy-economist and an expert in ethics. Quebec does not participate in the pCODR process and prior to early 2016, Quebec did not participate in the Patented Medicines Prices Review Board (PMPRB).

#WHOPAYSFORCANCER – A BREAKDOWN IN FUNDING

After Health Canada approval, cancer drugs are evaluated by the pan-Canadian Oncology Drug Review (pCODR), a program of the Canadian Agency for Drugs and Technologies in Health (CADTH) that provides recommendations to inform funding discussions for cancer drugs. In many aspects, **pCODR's process can be applauded** as its deliberative framework allows for patient and clinician input so that **patient-based values** and real clinical context can be reflected in the recommendations. Further, in an effort to reduce delays once Health Canada approval occurs, manufacturers can submit their file to pCODR six months prior to anticipated NOC/NOCc. However, as in the case of ceritinib, a **negative funding decision** places perhaps an **insurmountable barrier** to getting public coverage.

Even with a positive funding decision, manufacturers must successfully negotiate a price with the Patented Medicines Pricing Review Board (PMPRB) and then list in each province before treatments can be covered. This process results in **funding disparities** between provinces. For example, afatinib was publicly funded in Ontario 403 days after FDA approval and 291 days after Health Canada approval. Quebec was the last province to publicly fund afatinib. It was finally funded 1027 days after FDA approval and 915 days after NOC (and nearly two years after Ontario).

The reasons for the delays, negative decisions and delayed listings are many and start with the **differences between the Health Canada and FDA** approval systems. Health Canada has a priority review process to expedite new drug reviews for serious cases or areas of high need. However, questions have been raised about the speed and efficiency of this process. By comparison, the FDA has a three-pronged approach to drug expediency for serious life-threatening illnesses: fast track, accelerated approval and priority review.[30]

Traditionally, large randomized clinical trials used in phase 3 studies have been the **"gold standard"** for proving a drug's efficacy. Innovations in medicine are challenging that standard, particularly with the advancements in targeted therapy and the **high response rates** that are occurring in earlier phase trials. For example, in a recent phase 1 study of crizotinib, there was a 72% response rate and 19-month progression-free survival in patients with ROS1-rearranged non-small cell lung cancer, leading the FDA to approve crizotinib for this indication in March 2016.[31] As of yet, there has been **no such recommendation in Canada**.

Targeted therapies are a highly active area of lung cancer research. In fact, of the eight indications we reviewed for this report, five of them involved targeted therapies (afatinib, first- and second-line crizotinib, ceritinib and osimertinib). Of these, crizotinib, ceritinib and osimertinib were approved by Health Canada based on phase 1 and 2 data (good-sized trials, but not historically considered robust enough for policy). However, none has yet received a positive funding recommendation from pCODR based on these data. Crizotinib received a positive funding recommendation only after resubmitting with phase 3 data. pCODR's decision on osimertinib is still pending, as the manufacturer has **suspended the application**. In the negative funding decision for ceritinib, pCODR acknowledged that the drug "aligned with patient values and there was clear unmet need," however, they were not "confident of the net clinical benefit."[32] This mirrors the original crizotinib negative funding decision in which pCODR stated that, "conclusions drawn from non-randomized phase 2 studies were limited."[33]

Even when there is a positive funding recommendation, **significant time still passes** before pricing negotiations are completed and a drug is covered in each province. The causes for this delay are partly systemic, but the high cost of drugs is threatening to force patients to take on a significant financial burden or give up a chance at newer, more effective treatments.

Last year, a National Bureau of Economic Research study found anticancer drug prices, from launch increased by 10% every year between 1995 and 2013.[34]

After adjustment for inflation and survival benefits, this represents an $8,500 (USD) annual increase. These costs are **unsustainable for a public health care system**.

Lung cancer is a matter of life and death, and although the health system has measures and processes in place to ensure new medicines are closely scrutinized for efficacy and safety, **the system was not designed** to anticipate the specialized medicine renaissance we are currently witnessing. #Hope-is-Here, but it is costly. When patients receive a lung cancer diagnosis and are looking the disease in the face, they want access to the treatments that they and their medical team believe will give them the **best chance to live longer** and live well.

It is not only patients who are championing the need to evaluate our systems for drug approvals in Canada, there is also strong support from the medical community. Clinicians on the Lung Cancer Canada Medical Advisory Committee agree that there is a **need for a mechanism to access new treatments**, whether through trials or through other means as soon as there is compelling clinical evidence.

Lung cancer patients have no time to wait. There are many promising new treatments in the fight against lung cancer, yet **Canadian patients continue to wait** for access. The barriers are multiple and include governing bodies, new classes of treatments and evolving endpoints for trial success, and treatment costs. We need to work together to examine and address all factors so that these potentially life-saving medications can be brought to lung cancer patients before it is too late. Access and costs are issues that must be addressed – it cannot be **patients paying for these issues with their lives**. The time to advocate for change is now.

LUNG CANCER CANADA URGES ALL LEVELS OF APPROVAL AND PUBLIC FUNDING ASSESSMENT BODIES, INCLUDING HEALTH CANADA, PCODR AND INESSS TO TAKE A MORE PROGRESSIVE APPROACH IN THE EVALUATION OF TARGETED THERAPIES IN LUNG CANCER.

IAN AND CATHY MCALPINE OF MONTROSE, BRITISH COLUMBIA

Retirement is seen as the pinnacle, the 'golden years', a time to live your life and do exactly what you want to do, but this wasn't the case for Ian McAlpine. It was the first year of Ian and his wife Cathy's retirement and on their inaugural trip down south, Ian started to experience pain in his shoulder. Bewildered by the cause, Ian managed the pain until the couple sought medical advice when they arrived back in Canada. A healthy man and non-smoker, Ian was a key fixture at the gym and a kickboxing fanatic – lung cancer wasn't something on the list of possibilities.

Ian and Cathy McAlpine
of Montrose, British Columbia

Ian managed incredible pain while moving through the slow process of the Canadian system, to obtain a final diagnosis. Waiting continued to be a dominant theme in Ian's journey, as he waited for various scans that would confirm stage 4 lung cancer and chart his course of treatment.

After 42 years of marriage, Ian and Cathy were always a dynamic couple and this would be what ultimately saved Ian's life. The family was shocked to hear a lung cancer diagnosis and the weight of the news was devastating to their children and friends. The shock and awe turned into a fight to live, and with the support from his wife Cathy along with family, friends, and their health community, they both began the journey to survive.

Waiting was not acceptable and as Ian was heavily medicated to manage the extreme pain, Cathy took charge and pushed on all angles. This meant paying for tests so they didn't experience delays, seeking biomarker testing in the United States, asking many questions and looking into clinical trials for new therapies that were not yet available in Canada. This would be the treatment that would allow Ian to control his cancer.

Ian saw remarkable progress from a new-targeted therapy, he was able to build himself back up after the array of pain medications took a toll a significant physical toll and this inherent optimism drove his fight. A proud father and grandfather, Ian celebrates with his family and shares his story of courage with newly diagnosed patients to inspire hope. His message is simple - always remain hopeful and surround yourself with a strong group of supporters who can advocate on your behalf when you might not be able to do it yourself.

Figure 6 – Date of FDA approval to Health Canada approval

DRUG Generic name (brand name)	INDICATION	FDA APPROVAL DATE	ADDITIONAL DAYS UNTIL HEALTH CANADA APPROVAL DATE
afatinib (Giotrif)	First-line, EGFR+, ECOG 0-1	July 12, 2013[35]	**112**[36]
crizotinib (Xalkori)	Second-line, ALK+, ECOG 0- 2, with one prior chemotherapy treatment	August 26, 2011[37]	**243**[38]
crizotinib (Xalkori)	First-line, ALK+, ECOG 0-2	August 26, 2011[39]	**243**[40]
ceritinib (Zykadia)	ALK+, progressed on or intolerant to crizotinib	April 29, 2014[41]	**332**[42]
nivolumab (Opdivo)	Disease progression on or after cytotoxic chemotherapy and good performance status	March 4, 2015[43]	**359**[44]
osimertinib (Tagrisso)	EGFR T790M mutation +, who have progressed on or after EGFR TKI therapy	November 13, 2015[45]	**235**[46]
pemetrexed (Alimta)	Maintenance following first-line pemetrexed and cisplatin	July 2, 2009[47]	**1407**[48]
pembrolizumab (Keytruda)	Tumours express PD-L1, had disease progression on or after platinum-containing chemotherapy	September 4, 2014[49]	**589**[50]

Figure 7 – 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 [51]
afatinib (Giotrif)	First-line, EGFR+, ECOG 0-1	July 12, 2013	**403**
crizotinib (Xalkori)	Second-line, ALK+, ECOG 0-2, with one prior chemotherapy treatment	August 26, 2011	**767**
crizotinib (Xalkori)	First-line, ALK+, ECOG 0-2	August 26, 2011	**1558**
ceritinib (Zykadia)	ALK+, progressing on or intolerant to crizotinib	April 29, 2014	**885 and counting**
nivolumab (Opdivo)	Disease progression on or after cytotoxic chemotherapy and good performance status	March 4, 2015	**576 and counting**
osimertinib (Tagrisso)	EGFR T790M mutation +, who have progressed on or after EGFR TKI therapy	November 13, 2015	**322 and counting**
pemetrexed (Alimta)	Maintenance following first-line pemetrexed and cisplatin	July 2, 2009	**1705**
pembrolizumab (Keytruda)	Tumours express PD-L1, had disease progression on or after platinum-containing chemotherapy	September 4, 2014	**757 and counting**

ALK = anaplastic lymphoma kinase

ECOG = Eastern Cooperative Oncology Group

EGFR = epidermal growth factor receptor

TKI = tyrosine kinase inhibitor

Figure 8 – 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)	July 12, 2013	446	445	430	461	403	1027[52]	535	426	689	Not funded
crizotinib (Xalkori)	August 26, 2011	918	797	769	783	767	892[53]	828	805	949	956
crizotinib (Xalkori)	August 26, 2011	1746	1763	1773	1794	1749	1627[54]	Not funded	1879	1808	Not funded
ceritinib (Zykadia)	April 29, 2014	Not funded	Not funded	Not funded	Not funded	Not funded	Not Funded	Not funded	Not funded	Not funded	Not funded
nivolumab (Opdivo)	March 4, 2015	Not funded	Not funded	Not funded	Not funded	Not funded	Not Funded	Not funded	Not funded	Not funded	Not funded
osimertinib (Tagrisso)	November 13, 2015	Not funded	Not funded	Not funded	Not funded	Not funded	Not Funded	Not funded	Not funded	Not funded	Not funded
pemetrexed (Alimta)	July 2, 2009	1764	1764	1705	1795	1734	1917[55]	1734	1887	1734	2335
pembrolizumab (Keytruda)	September 4, 2014	Not funded	Not funded	Not funded	Not funded	Not funded	Not Funded	Not funded	Not funded	Not funded	Not funded

LUNG CANCER CANADA BELIEVES THAT IF WE LOOK AT THIS ISSUE FROM THE TOP DOWN, WE CAN ADDRESS ACCESS CHALLENGES TO BRING LIFE-SAVING TREATMENTS TO PATIENTS FASTER.

LAURA G. OF MONTREAL, QUEBEC

A child never expects to be put into the position of 'caregiver' for their parents, and Laura was no different. Laura achieved career success working at a high-profile law firm in Montreal and she just completed her Masters degree when she found herself in a self-described nightmare that she couldn't wake up from.

Laura G. of Montreal, Quebec

Laura has a twin sister and this was the extent of their family support, both sisters would soon become the hope that their mother would need as she embarked on a fight for her life. Initially, Laura and her sister thought this was a case of pneumonia, but at the age 60, her mother was diagnosed with small cell lung cancer, one of the more severe types of the disease.

The trio were shocked at the diagnosis and after the immediate devastation dissipated, Laura and her sister knew their mother needed their physical, mental and moral support and advocacy to fight this brutal disease. Both found it hard to watch this professional woman who had been their best friend, mentor and parent, struggle with a lack of treatment choices and a piecemeal view of her medical needs instead of enjoying a well-deserved retirement. They felt alone in helping her address the debilitating and lasting side effects of chemotherapy and radiation both on her body and her spirit. It was almost too much to witness!

Lung cancer has seen so many treatment advances that allow patients to fight the disease, but still remain active. This is not the case for small cell lung cancer, treatments are limited, and the standard treatment is aggressive and without regard for its lasting effects on the patient's quality of life. It can sometimes be a matter of quality versus quantity, says Laura. So many patients in Canada are asked to sacrifice their quality of life; to undergo "standard of care" treatments that are proven to not work and have significant side-effects. They do not have access to innovative treatments due to either a lack of trials or a lack of provincial drug plan coverage of new treatments.

This experience exposed Laura to the immense difficulties that lung cancer patients and their families have in navigating the medical system, advocating for the best treatments for themselves and living well with the disease. It also drove home the power of love, the strength of hope and the gift of cherishing and appreciating the good days with friends and family.

PART 5
CONCLUSION

#ACTIONTIME – THE VISION FOR LUNG CANCER IN CANADA

#Hope-is-Here. The spirit of the lung cancer community is strong and with the incredible progress that has been made with respect to awareness, screening and the development of new therapies, our **hope for the future is brighter than ever before**.

Despite the cracks and faults in the system, our community continues to advocate for change – **we will never waver!** Lung Cancer Canada is calling on the country's decision makers to **evaluate areas in the infrastructure that are not addressing the needs of patients and their caregivers**. Simply put, it is taking far too long for federal and provincial authorities to review, approve and fund new lung cancer treatments. We should not be in a position where patients, who are filled with hope, are dying while they wait for treatments that could give them a chance at more time with their family and friends. **The economics of lung cancer should never get in the way of allowing patients the right to live – there is no price tag on a life.**

Steadfast in the pursuit for a better lung cancer patient experience, the lung cancer community will continue its efforts to **break down the stigma barriers**, **facilitate faster diagnosis**, and **advocate for more timely access to available treatments**. The waiting game is not an option that patients are willing to accept – **it is time for action now**.

LUNG CANCER CANADA IS HOPEFUL AND OPTIMISTIC. LUNG CANCER CANADA UNDERSTANDS THE COMPLEXITIES OF THE DISEASE AND THE SYSTEMIC CHALLENGES. LUNG CANCER CANADA URGES DIALOGUE WTH DECISION MAKERS TO ADDRESS THE IDENTIFIED ISSUES. CANADA NEEDS A LUNG CANCER PLAN FOR THE FUTURE!

PART 6
WHO WE ARE

Lung Cancer Canada Board of Directors,
Staff and Friends at the TSX

#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 CANADA

AWARENESS. SUPPORT. EDUCATION.

WWW.LUNGCANCERCANADA.CA

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Corrections - The following corrections have been made and are reflected in the current version:

Page 20: Corrected text: The first edition incorrectly listed afatinib as receiving approval in 1407 days. This has been updated to 112 days and maintenance pemetrexed chemotherapy as 1407 days.

Page 21: Corrected text to Figure 5: The first edition reflected Patented Medicines Prices Review Board (PMPRB) as conducting pricing negotiations. This has been updated to accurately reflect the role of Pan Canadian Pharmaceutical Alliance and further clarify the role of the Institut national d'excellence en santé et en services sociaux (INESSS).

Page 25: Corrected text to Figure 6: Row 3 incorrectly stated the FDA Approval Date for first-line crizotinib as March 11, 2016 and has been corrected to August 26, 2011.

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