

2022 REPORT



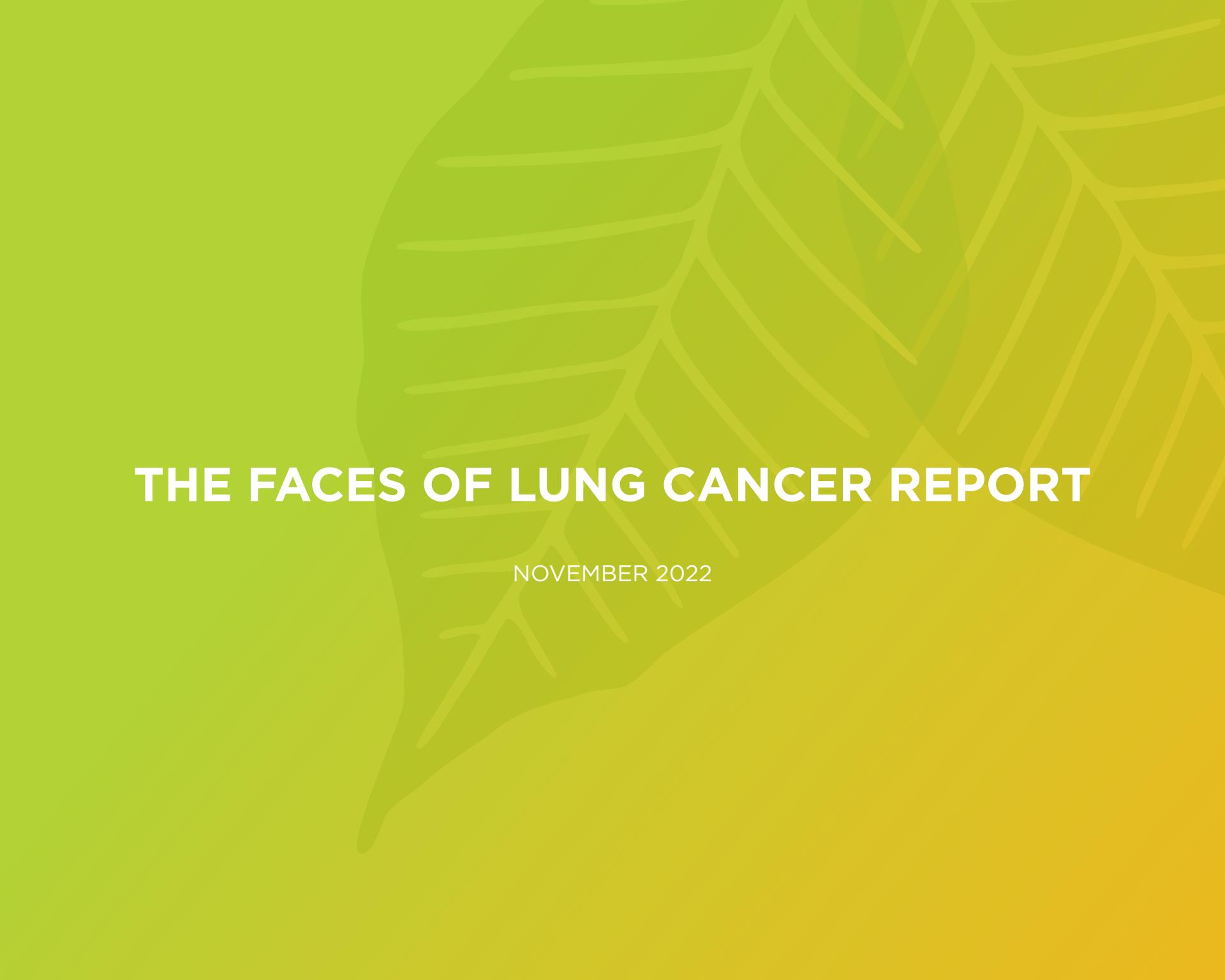
LUNG
CANCER
CANADA

CANCER
PULMONAIRE
CANADA

EQUITY IN LUNG CANCER: NAVIGATING A PATH FORWARD



FACES OF LUNG CANCER



THE FACES OF LUNG CANCER REPORT

NOVEMBER 2022

LUNG CANCER IN CANADA

Lung Cancer Canada is a national charitable organization that serves as a leading resource for lung cancer education, patient support, research and advocacy. We are a member of the Global Lung Cancer Coalition, and the only national organization focused exclusively on lung cancer – a leading cause of death in this country.

Lung Cancer Canada's mission is three-fold:

1

Increase public awareness
of lung cancer

2

Support and advocate
for lung cancer patients
and their families

3

Provide educational resources
to patients, family members,
health-care professionals,
and the general public.

We also offer a variety of resources to educate and support patients and their families:



Our website,
www.lungcancercanada.ca
a trustworthy source of
lung cancer information
and news



Our newsletter *Lung
Cancer Connection*,
which explores topics
of interest to the entire
lung cancer community



Our resource library
and patient stories,
which allows patients
and families to access
accurate information
and read stories of hope
from others facing a
similar diagnosis.



Our social media
conversation
 @LungCan
 @LungCancer_Can
 @lungcancercanada
 @lungcancercanada



Our Airways of Hope
program, which provides
patients with one-on-one
and group support with
a registered oncology
social worker



Our podcast, *Lung
Cancer Voices*, hosted by
Dr. Paul Wheatley-Price
features discussions with
healthcare providers,
patients and caregivers,
and lung cancer
researchers.

Each year, we publish the ***Faces of Lung Cancer Report***, through which we give a voice to the issues faced by patients and their families.
Thank you for taking the time to read, learn and advocate for those with this disease.

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Introduction



President's Letter

Dr. Stephanie Snow, President, Lung Cancer Canada

As I reflect on this past year and look ahead to 2023 at Lung Cancer Canada, my mind drifts to a particular patient I saw in my clinic recently. Let's call him John. He is a kind, gentle man in his 50s who I'd first met on the thoracic surgery inpatient floor – he was feeling unwell for weeks, but had no family doctor, so he visited a small rural hospital after-hours.

He presented with pulmonary symptoms, but staff had no access to radiology so they couldn't perform an X-ray or CT scan. They diagnosed John with pneumonia and sent him home with a prescription for antibiotics. Assuming he'd been treated, John took the drugs and waited for them to work – which they didn't.

Not long after, John fainted while helping a farmer erect a fence. He was brought to the larger regional hospital where staff found a large mass in the center of his chest, severely compressing his airways and major vessels to the heart. He was transferred to Halifax where a thoracic surgeon did a biopsy – John was diagnosed with small cell lung cancer. I went to see him the day we got the diagnosis, and he started chemotherapy the next day. He did well while in the hospital, and within a few days, he was well enough to go home.

When I saw John in clinic, despite significant improvements in his cough and breathing, he was having a rough time after leaving the hospital. He had nausea and pain but wasn't taking medications prescribed to relieve them. When he returned to the emergency department, John was very unwell, had a fever, low blood pressure, and was diagnosed with febrile neutropenia.



Dr. Stephanie Snow

Trying to figure out what happened, he lowered his head and spoke in a quiet voice, "Doctor, I can't read. I couldn't figure out what all those bottles of pills were for. I have no health insurance, so I also couldn't purchase the thermometer to check my temperature as the nurses had instructed, and still pay for my pills". He hadn't called the clinic for help because he had no funds to add to his pay-as-you-go cell phone plan – which is also why a community social worker couldn't reach him for follow-up.

"This is all my fault," John told me. "I'm sorry I caused you trouble."

In my practice I have many well educated, technologically adept, and passionate patients who turn into inspiring advocates. Many have volunteered with Lung Cancer Canada, using their personal journeys to spread hope and help others feel less alone. All of my patients get a copy of the Lung Cancer Canada patient guide, and I encourage them all to get involved in LCC's activities and to access the excellent support programs we have for patients across Canada, many of which are highlighted in this report.

But John isn't able to benefit from these resources and programs. Instead, he is the patient without a story – the other “face of lung cancer” that few see unless one is a health-care provider in this field. As detailed in Dr. Christian Finley’s piece in this report, social inequities and disparities in healthcare accessibility all-too-often inform a patient’s journey.

This year, Lung Cancer Canada held its 20th anniversary, a time of introspection and of growth. Our board held a strategic retreat to re-assess our goals and how to best engage all stakeholders in achieving them. To do so, as Dr. Paul Wheatley-Price writes in his piece, we ground ourselves in *why* this organization matters: to fully support every lung cancer patient and their families, to broaden awareness of the realities of this disease in communities, and to pursue a healthcare system and society where better and more accessible care is available.

Across Lung Cancer Canada is a renewed sense of purpose. Our growing team is planning in-person patient summits in Quebec while ensuring accessible French content in our patient stories and resources in an effort to bolster engagement in that province. We are strengthening partnerships, such as that with the Lung Health Foundation, forging new relationships with provincial lung associations, and designing more lung cancer awareness projects at a national level. We continue to expand activities during Lung Cancer Awareness Month, including a [webinar with CARP](#) and continuing *The Wrong Question* campaign. We are teaming with provincial planning committees to advocate for the establishment of lung cancer screening programs across the country. We are launching the Lung Ambition Alliance Awards, which will provide \$100,000 annually for research that targets earlier diagnosis, enhanced quality of care, and equitable access to care.

In this year's Faces of Lung Cancer Report, we celebrate our patients, share their stories, and instill a sense of hope for those touched by lung cancer. While I reflect on these stories and our goals moving forward, I feel the presence of my patient John next to me. As we cross our 20th anniversary and move forward into 2023, we must discover how to ensure we are reaching those Canadians who won't see this report – to make sure they feel a part of this community, to champion their voice and their story, and to advocate for their rights.



Part 1

Behind the Scenes at Lung Cancer Canada



Current State of Lung Cancer in Canada

Lung cancer remains the most commonly diagnosed cancer in Canada, with an estimated 30,000 new cases in 2022. While there has been an overall plateau in both diagnosis and mortality rates; unfortunately, 1 in 4, or 24% of cancer-related deaths in the country will be due to lung cancer among both men and women. The mortality rate for lung cancer is greater than all deaths related to breast, prostate, and colorectal cancers combined.

Still, the chances of surviving this disease have significantly improved in recent years. The five-year net survival rate of 22% in 2021 was an all-time high for our community, but this still lags in comparison to most other cancers. When taken as a whole, the average survival rate of cancer in general is 64%, leaving much room for continued improvement when it comes to lung cancer.

Far too many Canadians with lung cancer are diagnosed at a late and incurable stage, and much is needed to support them and their families, to improve access to treatments, to raise awareness, and to tackle the ongoing stigma associated with the disease.

Fortunately, research has led to the development of new treatments and emerging screening programs for early detection across the country. Eager scientists are studying better ways to tackle the etiology of lung cancer. Although it may be many years before lung cancer is a commonly curable or even chronic condition, new treatments such as targeted therapies and immunotherapy are improving and extending life for people living with the disease.

LUNG CANCER IN 2022...

1

MOST COMMONLY
DIAGNOSED
CANCER IN CANADA

30,000

CANADIANS
WILL BE DIAGNOSED
IN 2022

LUNG CANCER IS
THE CAUSE OF



24%

OF ALL
CANCER DEATHS

LUNG CANCER'S
SURVIVAL RATE IS



22%

COMPARED TO 64% FOR
ALL CANCERS COMBINED

LUNG CANCER AS
A PERCENTAGE



13%

OF ALL NEW
CASES OF CANCER

1 IN 15

CANADIANS
WILL DEVELOP
LUNG CANCER IN
THEIR LIFETIMES

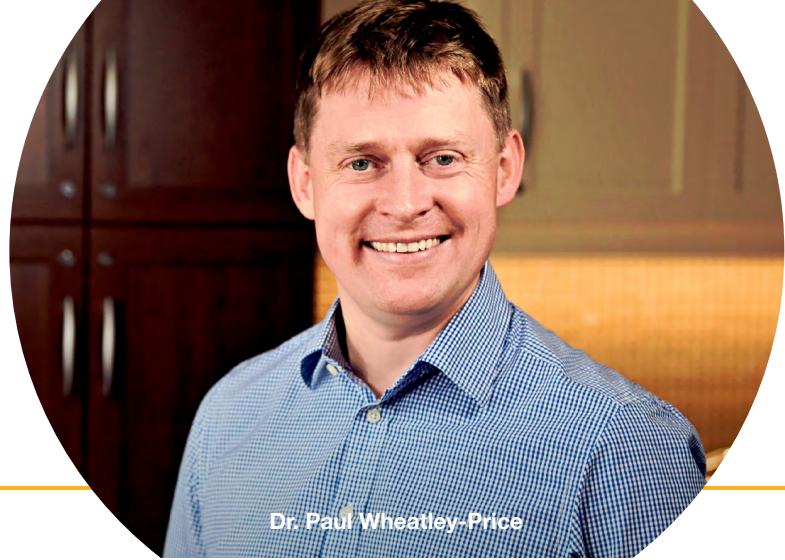
Lung Cancer Canada: The who and the why

Dr. Paul Wheatley-Price, Immediate Past President

In his book *Start with Why*, author Simon Sinek describes features of successful organizations, where there is a clear understanding of *why* they exist. That core essence of an organization, often described in a mission or a vision statement, can then inform and direct *how* the work is done. The '*what*' that actually happens becomes a natural and (hopefully) successful endpoint flowing from the *why* and the *how*. This is the story of Lung Cancer Canada, and we start with '*why*'.

Lung cancer is the most common cancer in Canada, and the most common cause of cancer deaths, both in Canada and around the globe. While the high prevalence of tobacco use remains the overwhelming leading cause of lung cancer, anyone who has lungs can get this disease – as evidenced by a significant proportion of people with no history of smoking who develop it. In fact, if 'never-smoking lung cancer' was classified separately, it would still remain in the top seven cancers in the country.

What does this mean for organizations like Lung Cancer Canada? First, it means that there isn't a large population of lung cancer survivors to call upon, although thankfully the survivor's voice is becoming louder and more apparent. Second, a proportion of the survivors are unable to get involved due to the inherent demographics of the disease. Lung cancer patients in general are likely to be older, less likely to have a college



Dr. Paul Wheatley-Price

education, and more likely to come from lower socio-economic groups. They may also have other medical conditions. While willing, they are not necessarily able to be a loud voice.

Stigma is a major challenge facing lung cancer. While cigarette smoking remains prominent in Canada, there have been significant public health strides over the decades in standardizing smoke-free environments. Yet, patients and family members with lung cancer still face stigmatization, whether they continue to smoke, worked hard to quit the most addictive of drugs, or never smoked at all in the first place.

So let's get back to the concept of Sinek – start with *why*. For lung cancer patients, is the *why* clear now?

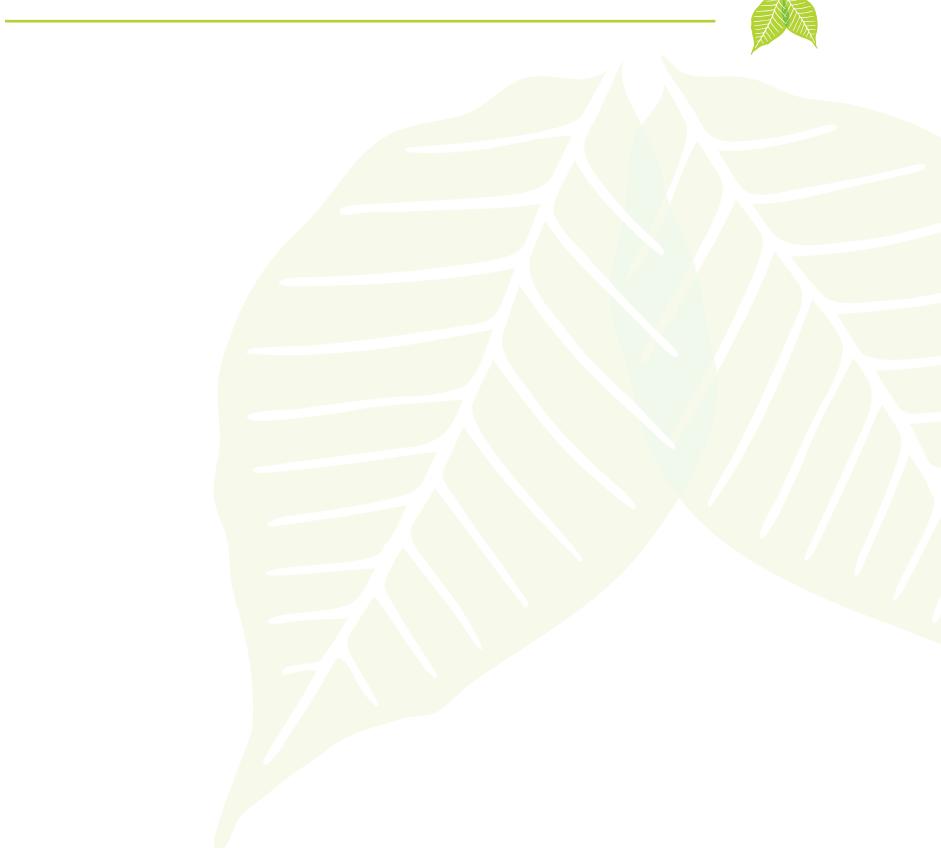
Lung Cancer Canada was formed to address these challenges and bridge these gaps. Founded in 2002 by Toronto radiation oncologist Dr. Yee Ung, oncology social worker Magdalene Winterhoff, and Ralph Gouda – who lost his wife to lung cancer – we were, for many years, a small organization, largely supporting the lung cancer community in Toronto. But over the past two decades, we have grown into a nationally recognized and respected charity.

Today, Lung Cancer Canada has a three-fold mission: to increase education and awareness of the disease, to support people living with lung cancer and their families, and to advocate for improved access to testing and treatments in all provinces and territories. Increasingly, we are also able to fund a number of lung cancer research projects.

The ‘how’ of the activities of Lung Cancer Canada is by identifying pillars of activity to focus on, and the ‘what’ are the programs that emerge from those pillars. For education, this includes publications and events. For support, this means fostering connections among peers and at the local level. For awareness, this means having a voice in education campaigns, talking to decision-makers, and engaging others in our work. For advocacy, this means a continuous effort to support regulatory approval of new therapies and to lobby (and indeed clash) with leaders

and regulatory bodies when needed. It means bringing the lung cancer community together through partnerships and collaboration to amplify our collective voice.

Lung Cancer Canada exists for you, the lung cancer community. Over the past 20 years, we have reached tens of thousands of patients and their families in one way or another. Yet there still are thousands and thousands who we have not yet reached or been able to support. For all of them, we are driven with purpose, passion and dedication to be a leading support, resource, and voice for those living with lung cancer.



So what does Lung Cancer Canada do?

We are Canada's leading and most trusted national resource for education, patient support, research and advocacy on lung cancer. Building upon our mission to support and advocate for patients and their families, and increase awareness and education of the disease, we offer a variety of resources and programs to do just that.



A lung cancer diagnosis and the treatments that follow have profound emotional, social, psychological, spiritual, and practical effects on health and well-being. *Airways of Hope* provides one-on-one support by oncology social worker, Elizabeth Dvergsten-Beauche, who helps patients and family members navigate mental and emotional concerns, day-to-day life, financial assistance, and bereavement. People who have used the program say that having an experienced social

worker to guide one through the healthcare system and provide encouragement is well-received and valuable. We have been delighted to add this service for our community this year.



Online support groups

Navigating a lung cancer diagnosis can feel lonely and connecting with others who have walked a similar path may help. Lung Cancer Canada's online patient support group, facilitated by our oncology social worker, meets monthly and is open to anyone in Canada. We also facilitate patient-led support groups in British Columbia, Alberta, and Ontario to provide more regional resources and connections. If you are interested in joining a group, or to help start a group in your area, [please reach out and connect with us](#).



Peer-to-Peer Program

Our Peer-to-Peer Program is facilitated by lung cancer survivors, family members and caregivers. Peer-to-peer navigators are volunteers who mentor, offer encouragement, advice, experience, and hope to those newly diagnosed or anyone needing support through a personal connection. Having someone who has lived a similar experience guide patients can be a vital link, whether by being an empathetic ear, navigating the logistics of treatment and care, or dealing with emotions that come with living with lung cancer. If you would like to access or offer peer to-peer support, [visit our website](#).



Lung Cancer Voices Podcast

Lung Cancer Voices is a podcast series hosted by Dr. Paul Wheatley-Price, medical oncologist at The Ottawa Hospital and past president of Lung Cancer Canada. Each month, Dr. Wheatley-Price sits down for an in-depth discussion with a leading lung cancer researcher, healthcare practitioner, person living with lung cancer, or a caregiver. They discuss current issues in lung cancer, relevant topics, and the patient and caregiver experience. Available online are more than 50 episodes produced since the podcast debuted in 2019.

We are delighted to soon launch a French-language podcast series in the coming months leading into 2023. Hosted by Dr. Nathalie Daaboul, hemato-oncologist at the Centre intégré de Cancérologie de la Montérégie and member of LCC's Medical Advisory Committee, Dr. Daaboul is passionate about highlighting the voices of Francophone and Québécois patients, caregivers, and health-care practitioners with the rest of Canada.



Stop Asking the Wrong Question Campaign

One of the most profound barriers and burdens for people living with lung cancer is the persistent stigma of lung cancer as a “smoker’s disease.” Too many people, after disclosing a lung cancer diagnosis, get asked, “Did you smoke?”, suggesting that their diagnosis was caused by smoking. The truth, however, is that anybody with lungs can get lung cancer. In a disease with a mere 22% five-year survival rate, compassion is crucial.

Our [anti-stigma campaign](#) run in partnership with the Lung Health Foundation is called: *Stop Asking the Wrong Question*. It urges people to ask, instead, the right question: Why aren’t people with lung cancer given a proper fighting chance as anyone else facing a cancer diagnosis?

#HOPEARMY

Lung cancer continues to be one of the most underfunded and stigmatized cancers, which hinders efforts for better screening, access,

and research. [Hope Army](#) is a social media campaign that recruits lung cancer supporters to spread awareness and education about the disease. Hope Army started with a month-long social media advertising campaign in November 2020 and has since recruited over 460 lung cancer advocates over numerous missions in the last few years, including a t-shirt design contest. The success of the first year led to a relaunch of the program in summer 2021 with a brand-new logo, new missions, and merch incentives for new recruits.



Research Funding

A large part of Lung Cancer Canada's work involves giving back to the lung cancer community, including those in research. Advancements in treatments and screening are the very reason the five-year survival rate for lung cancer is at 22% in 2021. This is the highest it has ever been, but still well below that of many other cancers.

Lung Cancer Canada is proud to support students, researchers, and scientists diving deeper into lung cancer research for many years, through awards such as the annual [Geoffrey Ogram Memorial Research Fund](#) and

summer studentships, with many more on the way, including the Lung Ambition Alliance Awards. We are proud to pave the way for the future of lung cancer research that will soon bring new biomarker testing guidelines, treatment options, and hope for patients and supporters across the country.



Patient Education

Any cancer diagnosis can leave patients and loved ones reeling – there is shock, anxiety, and a sense of helplessness and urgency. At Lung Cancer Canada, we make patient education a top priority, and we recognize that getting a life-changing diagnosis of lung cancer can be extremely overwhelming.

Our [Patient Support Guide](#) is available in English, French, and Traditional Chinese for free to patients and families both online and as a hardcopy that can be mailed directly to you. It touches on different aspects of what may come after your diagnosis and tips to navigate the cancer journey. To order a hard copy version of this guide, please [contact us](#).



Community Events

We have run lots of regional patient summits before the pandemic, and virtual events since. These will be coming back in person soon, so keep on the lookout for opportunities to attend. During Lung Cancer Awareness Month in November, we host many annual events, including our Evening of Hope, Stakeholder Briefing, and Patient Summit.

Each event presents a variety of inspirational patient stories, the latest updates in lung cancer treatments, practical advice on living with lung cancer, and the opportunity for patients, healthcare practitioners, and other stakeholders across Canada to connect with one another.



Advocacy Efforts

Behind the scenes, our [Medical Advisory Committee](#) – a team of volunteer health professionals and researchers – continuously advocates for all the best and newest treatments to be available to Canadians with lung cancer across all provinces and territories. This means meeting with local, regional, and federal politicians, and engaging with Canadian regulatory bodies to advocate for the approval of new treatments in lung cancer.

In the last year, this has been particularly focused on arguing for the expansion of formal lung cancer screening programs across the country, and providing clinician and patient input on the drug approval process for new treatments. *Part 3: Access to Treatments* details the developments in treatment access and public reimbursement of numerous lung cancer treatments over the last five years. There has been considerable progress over the years but still much work to do!

Pursuing Equity in Lung Cancer Care

Dr. Christian Finley, Thoracic Surgeon, McMaster University

The Canadian Partnership Against Cancer (CPAC) recently released its report on [Lung Cancer and Equity: A Focus on Income and Geography](#) as part of its four goals for cancer care:

- More equitable access to quality care
- Greater lung cancer prevention
- Improving survival rates
- Boosting quality of life among patients

Actioning its national strategy, CPAC clearly called out *equity* as a fundamental concern in cancer in Canada, particularly as it pertains to lung cancer care. As both one of the most common cancers and one that traditionally presents late, lung cancer kills more people than breast, prostate, and colon cancers combined.

What's more is that the most vulnerable patients carry the heaviest burden of this disease. Inequities in lung cancer risk factors, access to care, and other barriers are largely the result of social determinants of health, which impact some populations more than others. The CPAC report examined the challenges patients face at each step of the patient journey and how disproportionate barriers lead to decreased survival rates.



Dr. Christian Finley

Many of us naively think a health-care system like Canada's is fair and equitable; sadly, this is not the reality of the lived experience of many Canadians.

On a positive note, it is a time of great optimism with transformative innovation in all aspects of lung cancer care, from screening and minimally-invasive surgery to targeted radiation and remarkable new medications. The challenge now is to ensure we narrow the gap to ensure equity for all.

The impacts of inequity on lung cancer

The summative challenges faced by many results in decreased survival of lung cancer. For example, people are more likely to smoke if they have a lower income, or live in rural or remote areas, with the poorest almost twice as likely to smoke as those that are wealthier. As such, people are more likely to be diagnosed with lung cancer if they have lower income or live in rural or remote areas. Unfortunately, the rate of lung cancer is doubled in those with the lowest income compared to those with higher income. Adding to that burden, people with lung cancer who have lower incomes are more likely to be diagnosed with advanced (stage III or IV) disease.

These multiple inequities can be overwhelming to many who are trying to navigate the healthcare system. The reasons for this are complex, and include underpinnings of systemic racism, difficulty accessing care due to availability, and inflexible personal situations such as financial or employment barriers.

Even when people of lower income make it into the system with curable disease, their comorbidities, life circumstances and biases from health-care professionals further decrease their chances of curative intent therapies. Only 50 per cent of people with lower incomes diagnosed with stage I or II non-small cell lung cancer receive curative surgery compared with 68 per cent in high-income brackets. Overall, people with lower income are less likely to survive lung cancer, with 13 to 25 per cent less likely to survive three years post diagnosis.

The impact on Indigenous populations

Given that First Nations, Inuit and Métis are more likely to have lower incomes and to live in rural or remote communities, they likely make up a disproportionately high share of the population described in the CPAC report. While there is a need for greater Indigenous identifiers in research on cancer outcomes, available data does reveal significant inequities in health outcomes.

For example, compared to the non-Indigenous population in Canada, First Nations adults are 35 per cent less likely to survive lung cancer five years after diagnosis – even though they have similar lung cancer incidence rates. People living in Inuit Nunangat are more than twice as likely to be diagnosed with lung cancer. Métis adults are more likely to be diagnosed with lung cancer and are 30 per cent less likely to survive after five years.

Strengthening the availability of health data for these populations is needed to better understand their lung cancer journeys and to help close the health equity gaps experienced by First Nations, Inuit and Métis.

So what do we need to do?

To achieve equity in lung cancer outcomes, significant policy and system level action is needed to ensure underserved communities can access advances in cancer prevention, diagnosis and care. The report calls out Canada's health system leaders, decision-makers, and data custodians to:

1. Collaborate with organizations that represent underserved groups
2. Improve timely access to health, socioeconomic and environmental data and record linkages
3. Develop and implement standardized and validated identifiers of race and ethnicity
4. Support national and regional First Nations, Inuit and Métis governments and organizations.

The CPAC report is a call to action for Canadians that have been disadvantaged for too long. The hope is that by shining a light on these disparities, we will help narrow this persistent equity gap.



Part 2

The Lived Experiences of Lung Cancer



Tim Monds

Grassroots advocacy work breathes life into research and support

[Give a Breath](#), a 5 km fundraising walk/run originally founded by Tim Monds and his family in Edmonton has raised \$200,000 in donations and sponsorship for lung cancer in just four years.

This money has supported specialized thoracic equipment at the Royal Alexandra Hospital in Edmonton, funded research and clinical trials that focused on the early detection of lung cancer, and supported patient education and support groups.

At its inception, Give a Breath attracted several corporate sponsors including pharmaceutical giant AstraZeneca. In 2022, the fundraiser went national in a partnership with Lung Cancer Canada, with 215 participants in person and virtually.

Give a Breath is, at its foundation, a family affair. Tim, who lives with stage four non-small cell lung cancer, is supported by his wife Patty, their four children, spouses, grandchildren and friends across Canada.

“When I was first diagnosed with stage one lung cancer, the thought of doing advocacy work never crossed my mind,” says Tim. “I thought I’d be fine. When I was diagnosed a second time, this time with stage four, everything changed.”



Tim Monds and wife Patty

In 2016, Tim went to the hospital with chest and shoulder pain, worried it was a heart attack. Instead, it turned out to be the first sign he had lung cancer when a nodule was discovered on an X-ray. He was 57 and had never smoked.

Fortunately, it was caught early and had not spread to his lymph nodes. Tim had a left upper lobe lobectomy with follow up CT scans every three months that confirmed the cancer had not returned.

But in 2018, soon after retiring as a school superintendent for Parkland School Division near Edmonton, 11 new nodules were discovered on Tim’s remaining lobes. After a wedge resection on his middle right lobe, the surgeon confirmed the cancer had metastasized and he had developed stage four lung cancer.

“My surgeon said to me, odds are we’ll never talk about lung cancer again, but in 2018, I guess my body decided otherwise,” says Tim. “My immune system could not fight the return of the cancer.”

For the next two years, the nine remaining nodules grew slowly – a

good thing – but eventually enlarged and additional nodules were found. Biomarker testing not only showed Tim had high PDL-1 expression, but he was also positive for RET, a driver mutation that only appears in only 1-2% of lung cancer patients. These new discoveries prompted the start of immunotherapy treatment – pembrolizumab (Keytruda) – in March 2021.

With this new treatment that was tailored to his disease, Tim stabilized and his coughing settled down. After three months of treatment, the first CT scan showed nodules were shrinking and some even disappearing!

Going from thinking he would never have to worry about lung cancer to again being diagnosed with stage four just two years later was shocking – and he realized he had to learn to live with it.

“I started to learn more about lung cancer, the stigma that follows it, and the lack of equitable funding for supports, research, and ultimately a cure,” Tim says. “That spurred me to want to do more – so I spoke with my surgeon about our families’ plan to start a walk/run – ‘Give a Breath’, as well as raise awareness for lung cancer.

Tim’s advocacy work has gone far beyond his initial plans for *Give a Breath*. He now works with various organizations including Lung Cancer Canada, Lung Health Foundation and the Canadian Cancer Survivor Network, as well as volunteers for Alberta Cancer and serves as a patient advisor for an Alberta Health Services screening project.

“I have always been someone who has a purpose,” says Tim. “I couldn’t sit back and wait to hear there are no more options for treatment. I wanted to ensure others with lung cancer have options – and focusing on *Give a Breath* meant raising awareness, necessary funds and eliminating the stigma of smoking.”

Despite a retirement that now looks very different from the one he’d envisioned, Tim says he finds deep meaning from the work he is doing.

“Having cancer, and doing my best to make a difference for other people, feels right.” Tim says, adding that he continues to work on finding the balance between advocacy and living his own life.

“Talking about lung cancer almost every day can be physically and emotionally draining and sometimes I wish I could just forget about it. But putting my energy into this is necessary and essential to raising awareness and enabling the kind of research and supports needed for people with lung cancer.”

Lung Cancer Canada believes...

- Funding for lung cancer is underwhelming and for a long time has not been a priority for our governments. It continues to be one of the most underfunded cancers in Canada.
- Nobody should be alone in fighting lung cancer. Connecting with the greater Canadian community helps lend support to each other, while advancing the visibility of lung cancer in society. Patients like Tim are truly inspiring, as they are trying to motivate and help others, while living with lung cancer.
- Any advocacy effort helps, being on a smaller or much larger scale and can take on all shapes and sizes.
- Don’t hesitate to connect with groups available in your city, province, or through LCC to better know what’s available and what suits you better.

Tim is very proud of his family for organizing and promoting *Give a Breath*. They quickly surpassed their first year's goal of raising \$30,000, as family, friends, colleagues and other supporters stepped up to the plate.

It was Tim's vision to see *Give a Breath* go national. With the support of his amazing family and the partnership with Lung Cancer Canada, this has become a reality.

Mark your calendars for the next [Give a Breath 5k](#): June 3, 2023.



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Tim Monds

Leon D'Silva

Targeted therapy brings new hope to patients unresponsive to traditional treatments

Leon D'Silva was a 62-year-old self-described gym fanatic in great physical shape, living in Dubai with his wife and two sons, when the trajectory of his life changed in fall 2018.

It started with mild lower back pain that grew increasingly worse into the new year. He visited many doctors who, believing it to be a stress fracture, prescribed painkillers and physiotherapy.

But Leon was sure it was something different, and pressed for more imaging. Soon, an MRI and CT scan revealed two masses in his lower lung. He sought one of India's top oncologists in Bombay who ordered a PET scan: Leon was shocked to find it had spread much more than anticipated. Not only did he have tumours in both lungs, but he had them on his liver, across 13 vertebrae in his spine, several ribs, and on the scapula of the right shoulder. He also had a small nodule on his right hip.

"I was diagnosed with stage four non-small cell lung cancer, and the doctors told me I had three to six months to live," Leon says. "It was quite shocking to hear."

Nonetheless, Leon spent the next year and a half undergoing a dozen sessions each of chemotherapy and immunotherapy. While the tumours shrank in response, they kept returning. As Leon's quality of life dropped into pain and difficulty standing or sitting for long, he maintained his faith and his optimistic mindset – and decided to move across the Atlantic with his family and return to the country he left 20 years earlier.



Leon D'Silva and wife Lorraine

At Credit Valley Hospital in Mississauga, Ontario, Leon received further treatment – radiation and chemotherapy – that ultimately proved unsuccessful. In a fortuitous chance, he was referred to the Princess Margaret Cancer Centre where a special clinical trial was underway for a new medication.

There, he met oncologist and past president of Lung Cancer Canada, Dr. Natasha Leighl, who Leon says "radiated positivity" – a trait he values deeply and has exuded his entire life, lung cancer notwithstanding.

"A person truly needs a strong mindset, particularly during times like this," he says. "I believe it is extreme positivity that gets us through major challenges and helps medicine fight its way through."

"A person truly needs a strong mindset, particularly during times like this. I believe it is extreme positivity that gets us through major challenges and helps medicine fight its way through."

Leon D'Silva

Three years after Leon was given three months to live, he was able to access an expensive new targeted therapy after Dr. Leighl applied to the pharmaceutical company on compassionate grounds. That medicine was pralsetinib, a treatment for metastatic non-small cell lung cancer in cases where a patient has RET fusion-positive genes.

After balancing the new drug to an individualized dose level that spared Leon difficult side effects, pralsetinib has, by all accounts, been a massive success.

"It has worked like a miracle," he says. "I feel truly blessed to have received this trial medicine, and am grateful to the company and to the team at Princess Margaret Cancer Centre for advocating for me."

A remarkable turn of events

Before this therapy, Leon experienced extreme pain even by simply turning on his side while lying in bed. But only months later, Leon found himself able to walk nearly three kilometres several days a week, slowly and carefully. This is also owing to exercises he has learned at Toronto Rehab that have helped him ease some of the pain exposed by chemotherapy.

Most tellingly, scans in summer of 2022 revealed that the tumours in Leon's lungs, 13 vertebrae in his spine as well as a perforated T12 vertebrae had completely healed – a remarkable turn of events. Lesions in his liver shrunk a quarter in size, though by summer the liver tumour had grown. At the time of this writing in September 2022, doctors were set to perform a biopsy and Leon was gearing up for yet another round of chemotherapy.

"I think they will find that all the tumours are gone," he says, inherently positive as always. "I understand my body better and know the pain is less than it was. I am telling my mind it will be in remission."

As he continues with his targeted therapy, under the watchful eye of Dr. Leighl, her team, Leon says he is using visualization to help with his healing. The target of this practice: seeing himself return to the gym again.

"No one can win the war on their own," Leon says. "Without faith in God, faith in your doctors and medicine, healing is far away."



Lung Cancer Canada believes...

- Lung cancer is not one cancer but in fact many subtypes of lung cancer, each of which behaves differently and requires distinct therapy. Tailored treatment for people with incurable lung cancer is proven to help control cancer, reduce symptoms, improve quality of life and extend survival longer.
- Lung cancer patients deserve access to broad-based molecular testing (such as next generation sequencing) at the time of diagnosis of advanced or metastatic disease, if not early-stage setting.
- With rapid advances in identifying new molecular targets and therapeutics, markers untreatable today may be treatable in the near future.
- Drug availability differs from province to province as does reimbursement. Drug navigators in hospitals can help better understand what's available and actively work with the oncologist to access drugs.

Shannon McCrae

A fortuitous screening program catches B.C. woman's early lung cancer

Three years ago, Shannon McCrae's best friend Barbara suffered a sudden seizure that landed her in the hospital. Doctors ran tests and discovered that she had late-stage lung cancer that had spread to her brain. They tried immunotherapy and radiation, but it was too late.

"My friend, who I knew since childhood, died of a disease she had no idea she had," Shannon says. Barbara, 70, never experienced any symptoms of lung cancer.

Not long after, Shannon spotted an ad on social media inviting members of the public to join a new study at nearby Vancouver General Hospital: a screening program for lung cancer. The timely coincidence was not lost on her.

Though she also had no symptoms, and led a full life cycling, gardening, knitting and playing with her twin granddaughters, Shannon decided it couldn't hurt to apply. She had smoked for many years, after all.

"Barbara saved my life," she says.

British Columbia is the first in Canada to introduce a province-wide lung screening program. Funded by the government and several non-profit associations, it officially launched this past spring across 36 sites.

Using low-dose computed tomography (LDCT), they aim to screen nearly 10,000 patients by spring 2023. During the procedure, participants lie on a table and the scanner takes detailed images of their lungs in about 15 seconds.



Barbara and Shannon

"Here in B.C., seven people die of lung cancer every day – sadly because most cases are diagnosed at an advanced stage," says program director Dr. Stephen Lam, who is Shannon's oncologist and sits on the Medical Advisory Committee for Lung Cancer Canada.

"The Lung Screening Program aims to change this trend by detecting the majority of lung cancers at an early stage when treatment options are more varied and effective."

It's estimated that these screenings will initially diagnose about 150 lung cancer cases annually, rising to 300 by year eight – and more than three quarters of patients will be diagnosed at an earlier stage than had they not been screened. Patients like Shannon.

"Lung cancer is a silent killer. By the time they discover it, it's often too late. Screening can and will save lives, and it's a very simple test that only takes minutes out of your day."

Shannon McCrae

Click the video below to watch Shannon's story:

Shannon had joined a study prior to the screening program's launch, spurred by Barbara's shocking diagnosis and as a chance to be part of research that could help others.

After many months, it wasn't until the third screen that doctors saw a small mass in her lungs. In June 2020, another scan revealed that it had grown rapidly and was the size of a dime.

"At no point did I think they would actually find lung cancer," she says. "I was so shocked, for a few days, I lost my mind."

The good news is that this third screening session caught it very early. Only weeks later, in August 2020, Shannon had surgery to remove the tumor, and spent just a few days in hospital recovery. She has never needed any treatment, and now takes just one CT scan a year. In the end, she had lung cancer for an amazingly short few months.

"It is almost like a blur, like a dream – did that really happen?" Shannon says. Only when she went to donate blood in 2021 and she couldn't, owing to her status as a cancer survivor, was she taken aback.

This province-wide lung-screening program will provide equitable access for eligible British Columbians via a centralized program, resulting in improved survival rates thanks to early lung cancer detection.

"Lung cancer is a silent killer. By the time they discover it, it's often too

late," says Shannon. "Pre-screening can and will save lives, and it's a very simple test that only takes minutes out of your day."

Shannon feels that every province should be giving the same level of preventative care towards lung cancer as they do to other cancers like prostate and breast.

"Had Barbara not passed away from lung cancer, I wouldn't have joined this study, and that tumor would have grown," Shannon says. "It's kind of crazy. I certainly feel that everyone should have the opportunity to have pre-screening for lung cancer."



Lung Cancer Canada believes...

- The disease can strike any Canadian who may show no symptoms until the cancer spreads, at which point it can be too late.
- Early detection is vital to fostering better outcomes for Canadians.
- Lung cancer screening programs should eventually be accessible in both urban and rural areas like many other cancer screening programs.
- Clinical trials show that three low-dose CT lung scans over several years can save lives. Still, full funding for lung cancer screening has been granted only in B.C. and Ontario, with a pilot program now approved in Alberta. CT screening for lung cancer shouldn't be a distant dream as it is in the majority of provinces.

Terri Conneran



Patient advocacy group brings empowerment and connection worldwide

When she experienced laboured breathing and fatigue throughout the summer of 2016, Terri Conneran was treated for asthma. As her symptoms worsened into the fall, doctors suspected allergies, and after that, bronchitis. By Christmas, they believed she had pneumonia and ordered X-rays – which is what Terri believes saved her life, albeit in a roundabout way.

By imaging the fluid in her lungs, doctors identified a tumour that would otherwise have remained undetected. In the new year, Terri visited many specialists and had a biopsy before she was diagnosed with stage 3 lung cancer and adenocarcinoma.

"I was floored, caught completely off guard," she says. "I knew nothing about lung cancer."

Suddenly, Terri's care journey intensified. The plan was to remove a lung and perform followup chemotherapy. In the meantime, doctors ran initial biomarker testing and she recalls them telling her she didn't have any. But as she attended clinic for a preoperative appointment, she received word that her care team switched the plan from surgery to three rounds of chemotherapy, a sequence of events that left her spinning.

"I didn't feel like an empowered patient but rather someone just pushed through the system, bouncing like a pinball," Terri says. "I was overwhelmed, feeling out of control, and feeling sicker and sicker."



Terri Conneran and family

In the end, Terri had chemotherapy and a lobectomy to remove half her left lung. The journey left her desperately wanting to know more, to understand how she developed this disease.

As she started to connect with others in the lung cancer community, Terri was drawn to discussions about biomarkers, and she decided to seek a second opinion. This doctor confirmed she was indeed positive, for a biomarker called KRAS, a mere three years after her diagnosis and two recurrences later. This finding changed her treatment plan around and she felt relieved to finally see a path forward.

With newfound clarity, Terri says she felt empowered to learn as much as she could about biomarkers – but she couldn't find any patient groups that discussed KRAS even though it is the most common biomarker in lung cancer.

"I never thought I'd be involved in advocacy, because it felt too political. But really, it was about the willingness to share my voice to tell others that they will be okay, and to build a community of people."

Terri Conneran

Undaunted, she decided to launch her own group: [KRAS Kickers](#).

"I never thought I'd be involved in advocacy, because it felt too political," says Terri. "But really, it was about the willingness to share my voice to tell others that they will be okay, and to build a community of people."

KRAS Kickers connects people with any subtype of KRAS in any cancer. The key focus is on advocating for biomarker testing, which Terri has learned is crucial in order to get optimal, personalized treatment. Her group works with other groups to push for full diagnostics, including biomarkers.

"Patients need the right information about their disease," says Terri. "We share clinical trial news, do research, make connections and gather information so that we can spread it to our community and empower others. Our alliance with Lung Cancer Canada is one of many in this resource-sharing spirit."

Ultimately, Terri wants to ensure people know they're not alone in their cancer journey.

"It's cathartic to both talk to and hear from other people sharing similar experiences," says Terri. "It makes it feel more manageable, and changes the conversation from something that happened to you, to a 'how can we work together' narrative."

Today, KRAS Kickers has 1,500 members on its Facebook group, and 3,000 users on its website. Terri holds an annual event, in-person and online, and the first one in 2021 attracted people from across 10 countries. She hopes to expand the group, build more alliances, broaden access to resources, and engage more cancer survivors.

Terri's own journey has also taken a positive turn: Since her initial diagnosis in early 2017, she has had five recurrences of lung cancer necessitating further treatment. Still, today at her home in Charlotte, North Carolina, Terri has been in NED – "no evidence of disease" – for over a year.



Lung Cancer Canada believes...

- Research in lung cancer is essential in underpinning early detection, innovation, new therapies, supportive care, as well as education and advocacy. We need a greater commitment from all levels of government on funding research in lung cancer to improve these survival outcomes.
- Helping patients stay educated and informed is impactful for their journey.
- Every patient should be empowered with as much information and knowledge as possible to be active members of their own care teams
- Communities of support are essential for the mental health of lung cancer survivors.

Clare Ford

Unique exercise program underscores the role of physical activity for lung cancer survivors

The importance of physical activity is magnified for Canadians living with lung cancer. Yet because exercise can feel daunting, many don't prioritize it, leading to diminished quality of life and physical function.

A [review of studies](#) shows that exercise carries diverse benefits for lung cancer patients, including relieving treatment-related fatigue, improving mental health – and boosting both heart function and muscle strength, both key predictors of survival.

In fact, exercise training is increasingly playing a specific role in lung cancer care. This movement follows [substantial evidence](#) proving that exercise at any time in a patient's journey is effective in improving several outcomes. For example, [this study from Italy](#) shows that pre-surgery exercise leads to better treatment outcomes, fewer complications, and a shorter length of hospital stay.

As patients live longer in the shadow of lung cancer, it's important that they can access customized exercise programs. We must do more to provide equitable access to such programs to all Canadians.

Project EXCEL: Addressing the Accessibility Gap

One program developed out of the [University of Calgary](#) and funded by CIHR, CCS and the Alberta Cancer Foundation is seeking to fill that gap.

EXercise for Cancer to Enhance Living well – or “[EXCEL](#)” – is a four-



Clare Ford

month program that combines aerobic, resistance, balance, and flexibility exercises. In a small group format, in-person and online, workouts are tailored to meet the needs of each person and their specific cancer type in order to promote fitness and wellness benefits.

Led by principal investigator Dr. Nicole Culos-Reed, EXCEL began in 2020 with the goal of bringing such programs to rural and remote cancer survivors, and to encourage participants to become life-long exercisers. That's because cancer survivors tend to experience more

“When we tailor exercise programs to meet the unique needs of lung cancer patients, we see a host of benefits for physical and mental health. There is a sense of control that can be taken away with cancer, and fitness gives back something that can be controlled.”

Dr. Nicole Culos-Reed

negative effects after treatment and are overall less healthy than their urban counterparts.

"A growing body of evidence shows that when we tailor exercise programs to meet the unique needs of lung cancer patients, we see a host of benefits for physical and mental health," says Dr. Culos-Reed.

"There is a sense of control that can be taken away with cancer, and fitness gives back something that can be controlled. We know that living better through treatment, and having enhanced quality of life is related to survival outcomes – and we're consistently seeing positive associations between being physically active and better long term outcomes, including reduced deaths from cancer and from any cause."

By offering virtual programs, the EXCEL team is improving access to customised exercise programs in a greater bid to enhance cancer survivorship, help participants improve overall well-being, and open up a supportive network.

Clare Ford, diagnosed in June 2021 with stage one adenocarcinoma, has reaped the benefits of both fitness and support from the EXCEL program.

Clare's diagnosis came as a surprise as, despite spots on her lungs caught by a CT scan many years before, she had no symptoms and was in good physical health. Though Clare is an avid field hockey player, hiker and swimmer, she nonetheless feels fortunate to have found the EXCEL program.

While Clare lives in an urban centre, she was drawn to EXCEL because it featured a program specific to lung cancer. For her, it is a proactive investment in her future health.

"I'm not on any targeted therapy or chemotherapy, but one day I may be," she says. "Exercise is the most important thing I can do for myself, because if my disease does progress I will get through treatment better, I will recover more quickly from surgery, and I will cope better with stress and anxiety."

Clare says that connections with others through EXCEL keeps her hopeful. She says she is inspired by those with more advanced stage cancer who are mitigating the side effects of treatment through exercise. "My friend Angus, for example, who introduced me to the program - he is at stage 4 and it's so inspiring."

Angus Pratt says he was in good shape before he started the program – or so he thought. "When I saw the improvement from the baseline to the final evaluation, I was blown away by the improvement," he says. "Probably the most dramatic was in simple balance, but my core fitness, cardio and strength have all improved as well."

Angus says the fact that EXCEL is tailored to the specific needs of cancer patients is a key component to the success of the program.

"Aside from the exercises alone, the simple recognition of the struggle with down days due to treatment and other potential challenges is phenomenal," says Angus. "Plus, the social interaction and support is invaluable – in fact, the accountability is surprising. Knowing that people are going to ask if I'm keeping up with my routine has spurred me many times to keep going."

EXCEL has equally demonstrated the value of peer support and mentorship for Clare, who says she really enjoys connecting with the lung cancer community in such a positive way.

"It's two hours of my week that I really look forward to – it's a really supportive environment that's always followed by a conversation afterward with people who really understand the cancer journey" says Clare. "Furthermore, my post program assessment showed improvements in my resting heart rate, shoulder range of motion and aerobic fitness."

The EXCEL program continues to accept new patients. Canadians interested in participating can reach out via the [University of Calgary website](#).



Lung Cancer Canada believes...

- Physical activity is important for everyone, and that very much includes Canadians who live with lung cancer.
- There is an ongoing need for equitable access to lung-cancer specific exercise programs across Canada.
- We must pursue greater collaborations between physicians and cancer exercise specialists in order to develop personalized programs tied to individual needs, preferences, and health status.
- Canadians with lung cancer are encouraged to build exercise into daily routines to not only boost their quality of life, but also reduce their risk of complications from treatment and other health problems.

Jacques Morand

The journey of a Quebecois patient's unlikely path to lung cancer screening

When Jacques Morand went to his sleep apnea screening appointment in December 2021, he had no inkling of what was about to happen.

The next month his respirologist, Dr. Nicole Ezer at McGill University Health Centre, discussed the results of his polysomnography. She suggested he consider taking part in a lung cancer screening demo project. This pilot project, developed by the Ministry of Health of Québec, had just launched a few months earlier in a few hospitals across the province.

Jacques was very interested in the screening project and decided to give it a try. As an active smoker since his teens, he knows that lung cancer is a risk. He had talked to his family physician about screening in the past, who informed him that there was no structured program in place in Québec at the time.

In May 2022 Jacques came across an ad about the same screening project that Dr. Ezer had mentioned. He took this as a sign, spoke to his wife, and contacted the health team.

He was soon in touch with nurses from the coordination center, who confirmed he was eligible to participate and was referred to the nearest hospital. A mere ten days later, he had the low dose CT scan, which turned out to be quick and easy.



Jacques Morand and wife Sylvie

A turn of events...

As Jacques looked ahead to summer plans with his family in Gaspé, he received a phone call two weeks after the scan. The team had found an abnormal spot on his lung, and suspected it was cancerous. Jacques, who has a hearing impairment, thought that it was only a possibility, but his wife understood that it was more than that. She had the difficult task of explaining to him again what the doctor had said.

While he recognized lung cancer was a risk, Jacques was shocked because he was in good shape and had no symptoms. Anxiety and stress slowly set in as more tests were ordered, and Jacques was

"If you're eligible for lung cancer screening, don't hesitate to go. It doesn't hurt to have a CT scan. And if you are given the unfortunate news, the earlier the cancer is caught, the better."

Jacques Morand

grateful that he had close support from his wife Sylvie who he calls his "pillar." With the understanding of the on-site team, Jacques and his wife try to bundle as many tests together as possible during their several trips to the Gaspé Peninsula through the summer.

On August 10, 2022, the couple learned of Jacques' formal diagnosis of lung cancer. Fortunately, the 2.5 cm tumor was caught at an early stage, and thus surgery was an option – and it was set for November.

"I am not in control, but the doctors are there, and I trust them," Jacques said.

He has since stopped smoking, hoping this time it will be for good. "There's always a risk of going back to the cigarette. But when they tell you you're going to lose a lung, it's a big blow", he says.

Describing himself as resilient, he remains optimistic and positive about the future. Jacques and Sylvie say they are relieved that the cancer was diagnosed early, as his story would have been a lot different without the proposed screening.

He encourages anyone potentially eligible to contact the project line or to talk to their physician directly - it can be life changing. "Don't hesitate to go. You need to get answers either way. Don't leave any doubt. It doesn't hurt to have a CT scan. And if you are diagnosed with cancer, the earlier it's caught, the better."



Lung Cancer Canada believes...

- Screening saves lives: it is proven effective to reduce mortality by lung cancer
- Government-funded screening programs are different in every province, don't be afraid to discuss it with your physician and health-care team.
- Over time, investing in screening will eventually reduce the cost of treatment within health-care budgets over time.
- Smoking cessation is key and always encouraged. It's never too late to stop smoking. Don't hesitate to seek help, if needed.

The Lung Cancer Screening Demonstration Project offers a set of services to Quebecers aged 55 to 74 who are at high risk of developing the disease to screen for lung cancer and reduce the risk of developing it or dying from it. Eligible participants receive annual low-dose CT scans. For more information, visit the [program site](#).

Snapshot: Chantal Brunet

In Their Words...

My name is Chantal Brunet and back in January 2020, I celebrated my 50th birthday. I was married back in 1994 and I have two boys. I was at the top of my game, working in commercial real estate and was a Zumba instructor three times a week. I have always been healthy, and am a non-smoker. I was right where I wanted to be and happier than I had ever been.

Around the middle of February, I developed a cough. I coughed non-stop and started having chest pains. About two to three weeks later, after a few doctor appointments and some medications that didn't work, I was hit with the diagnosis: stage IV NSCLC lung cancer. The culprit? A 7.5 centimeter tumour in my right lung.

While waiting for the biopsy results, I started chemotherapy (cisplatin/pemetrexed). I was not doing very well – I had trouble breathing, shortness of breath, and I coughed a lot. At that point, my reaction was to pull out my boxing gloves and get ready to fight the enemy - I was in for a bitter battle. After undergoing two treatments, I got the biopsy results: EGFR mutations, Exon 18 and Exon 21. The rarest and least studied mutations, the big ticket!



Chantal Brunet

After two rounds of chemotherapy, I moved to a variety of different treatments, including:

- 7 months of osimertinib (Tagrisso) → disease progression and brain metastases
- 4 treatments of chemotherapy and simultaneous radiation therapy to the brain and spine → stable, whereas I would have hoped for tumour shrinkage
- A minimally invasive procedure to help stabilize my spine, called vertebroplasty
- 5 treatments of chemotherapy and pelvic radiation therapy → accompanied by loss of hair then major disease progression. This was the summer of 2021.

At that point, I did not have many options left. I approached a hospital in Boston with the help of my oncologist, Dr. Nathalie Daaboul. I asked for a second opinion and after a biopsy, I was missing one very specific mutation to access immunotherapy or any clinical trial.

So, my doctors put some very high hopes in a targeted therapy drug, afatinib. After my first scan, the results were quite encouraging. I even drove to Florida for a month. I had a lot of energy and I walked 10,000 steps a day.

When I returned to Canada in February 2022, CT and MRI scans showed slight progression of the tumour and metastases in the brain.

I was offered radiation therapy directly to my brain and lung, which meant I also had to stop treatment with afatinib. Along the way, I started having intense pain in my lower abdomen and back, which was discovered to be a metastasis lodged in my spinal cord. I was now numb from my lower back to my toes, and I could no longer walk on my own. I received emergency radiation therapy to the spine in hopes of regaining control of my legs. Finally in April 2022, I was admitted for eight days to control the pain and do physiotherapy.

By May, an MRI revealed that I had more than 25 metastases in the brain. I was to undergo a final series of radiation therapy treatments. I lost my hair again, with no guarantee that it would grow back. Fatigue was the main side effect - I think I slept all summer! I then went back on osimertinib at my request since it was the only drug that could protect the brain.

Now at the time of this writing in October 2022, I am still very much alive and I continue to take osimertinib because surprisingly, my latest scan showed a decrease in the tumour size and no new metastases! I walk without help, although my left leg and right foot are still numb. For longer distances, I use a walker or wheelchair, and my hair has slowly started to grow back. My bones, my hip and my lower back still hurt, but I take medications to control the pain.

If, at the beginning of this journey, I was ready to fight AGAINST cancer, I'm not there anymore. It takes too much energy. I have chosen to live WITH cancer, to co-exist with it, to make it an ally. To live my life while accepting that it has its own room inside of me. I will die anyway, but I don't want to die having LOST the battle. That's too negative. I will die having WON my journey with cancer. Dying is not a defeat - dying is a fact. So, I want to die having lived the best life possible.

I have read and meditated a lot throughout my journey. I have found great comfort in the power of living in the present moment. Never during my journey have I ever given up. Yes, I have mourned my sorrows, my suffering, and my grief - I had to. But I don't linger with that state of mind. I live here, in the now, and I must admit that cancer, in some odd way, has been a gift in my life. I am a better person. I no longer seek the approval of others. Looking good is not important to me anymore. It's too painful.

Today, I LIVE each day as if it were my last, within my capabilities. As my psychologist would say, “Make the best of a difficult situation”. So, every day I take the best moments of my day and enjoy them immensely. And it's not one day at a time, it's one *beautiful* day at a time.

Choosing means to give up something. I didn't choose cancer obviously, but it is here, and I have to deal with it. By choosing to live happily, I am giving up the choice to live in worry and suffering while waiting for death.

Here and now is all we have, and it's much less painful to focus on the present than hanging on to the past or living in fear of the future. That's how I'm choosing to live my life – one beautiful day at a time.



Lung Cancer Canada believes...

- Molecular testing is key to better identify the most effective and safest treatment available; it should be offered to all patients with lung cancer.
- Shared decision making is important all along the course of lung cancer treatment.
- Keeping an active and open discussion with your oncologist is crucial to try find the treatment that may suit you best.

Part 3

Access to Treatment



Table 1 — Status of CADTH Drug Reimbursements (Within the Last 5 Years)

DRUG Generic name (Brand name)	INDICATION	FDA APPROVAL DATE	HEALTH CANADA APPROVAL DATE	CADTH Status	Phase Data Used
alectinib (Alecensaro®) 1 st line	For the first-line treatment of patients with anaplastic lymphoma kinase (ALK) positive, locally advanced or metastatic NSCLC.	November 6, 2017	June 11, 2018	Final Recommendation July 25, 2018: Recommended pending cost-effectiveness	3
amivantamab (Rybrevant®)	For the treatment of adult patients with locally advanced or metastatic non-small cell lung cancer (NSCLC) with activating epidermal-growth factor receptor (EGFR) Exon 20 insertion mutations whose disease has progressed on, or after platinum-based chemotherapy.	May 21, 2021	March 31, 2022	Currently under review	1
atezolizumab (Tecentriq®) SCL	For the first-line treatment of patients with extensive stage small cell lung cancer (ES-SCLC) in combination with a platinum-based chemotherapy and etoposide.	March 18, 2019	August 8, 2019	Final Recommendation Sept 30th, 2022: Recommended pending cost-effectiveness	3
Atezolizumab (Tecentriq®) Adjuvant	For adjuvant treatment following resection and platinum-based chemotherapy for patients with stage II to IIIA NSCLC whose tumours have PD-L1 expression on ≥ 50% of tumour cells (TCs).	October 15, 2021	January 14, 2022	Final Recommendation Sept 30th, 2022: Recommended pending cost-effectiveness	3
atezolizumab (Tecentriq®) 2 nd line	For the treatment of patients with locally advanced or metastatic NSCLC who have progressed on or after systemic chemotherapy until loss of clinical benefit.	October 18, 2016	April 6, 2018	Final Recommendation June 20, 2018: Recommended pending cost-effectiveness	2 + 3
Atezolizumab & Bevacizumab (Tecentriq® & Avastin®)	For the treatment of metastatic EGFR and/or ALK positive non-squamous non-small cell lung cancer in patients who have progressed on treatment with targeted therapies.	December 6, 2018	May 24, 2019	Final Recommendation: July 3, 2020 Not recommended.	3
Bevacizumab (Mvasi®)	For treatment of patients with unresectable advanced, metastatic or recurrent non-squamous non-small cell lung cancer, in combination with carboplatin/paclitaxel chemotherapy regimen.	September 14, 2017	April 30, 2018	Final Recommendation: Final Biosimilar Dossier Issued January 14, 2019	1 + 3
Bevacizumab (Zirabev®)	For the treatment of patients with unresectable advanced, metastatic or recurrent non-squamous non-small cell lung cancer, in combination with carboplatin/paclitaxel chemotherapy regimen.	June 27, 2019	June 14, 2019	Final Recommendation March 28, 2019: File closed	3
brigatinib (Alunbrig®) 1 st line	For the treatment of adult patients with anaplastic lymphoma kinase (ALK)-positive locally advanced (not amenable to curative therapy) or metastatic non-small cell lung cancer (NSCLC) previously untreated with an ALK inhibitor.	May 22, 2020	March 3, 2021	Final Recommendation April 21, 2021: Recommended	3
brigatinib (Alunbrig®) 2 nd line	For the treatment of adult patients with ALK positive metastatic NSCLC who have progressed on or who were intolerant to an ALK inhibitor (crizotinib).	April 28, 2017	July 26, 2018	Final Recommendation August 1, 2019: Not Recommended	2

Continued... Table 1 — Status of CADTH Drug Reimbursements (Within the Last 5 Years)

DRUG Generic name (Brand name)	INDICATION	FDA APPROVAL DATE	HEALTH CANADA APPROVAL DATE	CADTH Status	Phase Data Used
Capmatinib (Tabrecta®)	For the treatment of adult patients with locally advanced unresectable or metastatic non-small cell lung cancer (NSCLC) harbouring mesenchymal–epithelial transition (MET) exon 14 skipping alterations.	May 6, 2020	May 26, 2022	Not yet listed	2
cemiplimab (Libtayo®)	For the first-line treatment of adult patients with non-small cell lung cancer (NSCLC) expressing PD-L1 in ≥ 50% of tumour cells as determined by a validated test, with no EGFR, ALK or ROS1 aberrations, who have locally advanced NSCLC who are not candidates for surgical resection or definitive chemoradiation, or metastatic NSCLC.	February 21, 2021	October 26, 2021	Final Recommendation June 2, 2022: Recommended pending cost-effectiveness	3
crizotinib (Xalkori®) ROS1	As a single agent as first-line treatment for patients with ROS1 positive advanced NSCLC.	March 11, 2016	August 28, 2017	Final Recommendation May 23, 2019: Recommended pending cost-effectiveness and feasibility of adoption (budget impact)	1 + 2
dabrafenib (Tafinlar®) & trametinib (Mekinist®) 2 nd line	In combination for the treatment of patients with metastatic NSCLC with a BRAF V600 mutation (previously treated with chemotherapy).	June 22, 2017	May 16, 2017	Final Recommendation November 2, 2017: Not Recommended	2
dabrafenib (Tafinlar®) & trametinib (Mekinist®)	For the treatment of patients with metastatic non-small cell lung cancer (NSCLC) with a BRAF V600 mutation and who have not received any prior anti-cancer therapy for metastatic disease.	June 22, 2017	May 18, 2018	Final Recommendation May 28, 2021: Notification to implement issued	2
durvalumab (IMFINZI®) Stage III unresectable NSCLC	For the treatment of patients with locally advanced, unresectable Stage III non-small cell lung cancer (NSCLC) whose disease has not progressed following platinum-based chemoradiation therapy	February 16, 2018	May 4, 2018	Final Recommendation: May 3, 2019 Recommended for reimbursement	3
durvalumab (IMFINZI®) ES-SCLC	First-line treatment of adult patients with extensive-stage small cell lung cancer (ES-SCLC) in combination with etoposide and either carboplatin or cisplatin	March 30, 2020	September 21, 2020	Final Recommendation July 27, 2021: Recommended for reimbursement	3
entrectinib (Rozlytrek®) ROS1	For the first-line treatment of adult patients with ROS1-positive locally advanced or metastatic non-small cell lung cancer	August 15, 2019	May 5, 2020	Final Recommendation January 27th, 2021: Recommended pending cost-effectiveness	1 + 2

Continued... Table 1 — Status of CADTH Drug Reimbursements (Within the Last 5 Years)

DRUG Generic name (Brand name)	INDICATION	FDA APPROVAL DATE	HEALTH CANADA APPROVAL DATE	CADTH Status	Phase Data Used
entrectinib (Rozlytrek®) NTRK	For the treatment of adult patients with unresectable locally advanced or metastatic extracranial solid tumours, including brain metastases, that have a neurotrophic tyrosine receptor kinase (NTRK) gene fusion without a known acquired resistance mutation, and with no satisfactory treatment options.	August 15, 2019	January 20, 2020	Currently under review	1 + 2
larotrectinib (Vitrakvi®)	For the treatment of adult and pediatric patients with solid tumours that have a Neurotrophic Tyrosine Receptor Kinase (NTRK) gene fusion without a known acquired resistance mutation, are metastatic or where surgical resection is likely to result in severe morbidity, and have no satisfactory treatment options	November 26, 2018	July 10, 2019	Final Recommendation September 13, 2021: Recommended pending cost-effectiveness	1 + 2
lorlatinib (Lorbrena®) 1 st line	For the first-line treatment of adult patients with anaplastic lymphoma kinase (ALK)-positive locally advanced (not amenable to curative therapy) or metastatic non-small cell lung cancer (NSCLC)	March 3, 2021	June 7, 2021	Final Recommendation: April 4, 2022: Reimburse with conditions	3
lorlatinib (Lorbrena®) 2 nd line	For the treatment of adult patients with ALK positive metastatic NSCLC who have progressed on crizotinib and at least one other ALK inhibitor, or patients who have progressed on ceritinib or alectinib.	November 2, 2018	February 22, 2019	Final Recommendation January 30, 2020: Not recommended	2
lurbinectedin (Zepzelca®)	Treatment of adult patients with Stage III or metastatic small cell lung cancer (SCLC) who have progressed on or after platinum-containing therapy.	June 15, 2020	September 29, 2021	Currently under review	2
nivolumab (Opdivo®)	For neoadjuvant treatment of adult patients with resectable NSCLC (tumours ≥4cm or node positive) when used in combination with platinum-doublet chemotherapy.	March 4, 2022	August 23, 2022	Currently under review	3
Nivolumab- Ipilimumab (Opdivo - Yervoy) NSCLC	Nivolumab, in combination with ipilimumab and 2 cycles of platinum-based chemotherapy for the first-line treatment of patients with metastatic or recurrent NSCLC with no EGFR or ALK genomic tumor aberrations	May 26, 2020	August 6, 2020	Final Recommendation March 4, 2021: Recommended pending cost-effectiveness	3
Nivolumab- ipilimumab (Opdivo- Yervoy) Malignant Pleural Mesothelioma	OPDIVO, in combination with ipilimumab, is indicated for the treatment of adult patients with unresectable malignant pleural mesothelioma (MPM) who have not received prior systemic therapy for MPM.	October 2, 2020	June 2, 2021	Final Recommendation August 4, 2021: Recommended pending cost-effectiveness	3
osimertinib (Tagrisso®) 1 st line	For the first-line treatment of patients with locally advanced or metastatic NSCLC whose tumours have EGFR mutations.	April 18, 2018	July 10, 2018	Final Recommendation January 4, 2019: Recommended pending cost-effectiveness	3

Continued... Table 1 — Status of CADTH Drug Reimbursements (Within the Last 5 Years)

DRUG Generic name (Brand name)	INDICATION	FDA APPROVAL DATE	HEALTH CANADA APPROVAL DATE	CADTH Status	Phase Data Used
Osimertinib (Tagrisso®) 2nd line	Osimertinib is indicated for the treatment of patients with locally advanced or metastatic EGFR T790M mutation-positive NSCLC whose disease has progressed on or after EGFR tyrosine kinase inhibitor (TKI) therapy	November 13, 2015	July 5, 2016	Final Recommendation May 4, 2017: Recommended for Reimbursement	3
osimertinib (Tagrisso®) adjuvant	Osimertinib is indicated as adjuvant therapy after tumour resection in patients with stage IB-IIIA (AJCC 7 th ed.) non-small cell lung cancer (NSCLC) whose tumours have epidermal growth factor receptor (EGFR) exon 19 deletions or exon 21 (L858R) substitution mutations	December 18, 2020	January 3, 2021	Final Recommendation January 10, 2022: Recommended for Reimbursement with conditions	3
pembrolizumab (Keytruda®) Non-squamous NSCLC	In combination with pemetrexed and platinum chemotherapy, for the treatment of metastatic non-squamous NSCLC, in adults with no EGFR or ALK genomic tumor aberrations, and no prior systemic chemotherapy treatment for metastatic NSCLC.	August 20, 2018	March 13, 2019	Final Recommendation May 31, 2019: Recommended pending cost-effectiveness	3
pembrolizumab (Keytruda®) Squamous NSCLC	For the treatment of patients with metastatic squamous NSCLC in combination with carboplatin and either paclitaxel or nab-paclitaxel, in adults with no prior systemic chemotherapy treatment for metastatic NSCLC	November 2, 2018	July 4, 2019	Final Recommendation January 3, 2020: Recommended pending cost-effectiveness	3
pralsetinib (Gavreto®)	Gavreto is indicated for the treatment of adult patients with rearranged during transfection (RET) fusion-positive locally advanced unresectable or metastatic non-small cell lung cancer (NSCLC)	September 4, 2020	July 21, 2021	Final Recommendation September 29, 2022: Recommendation pending cost-effectiveness	1 + 2
selpercatinib (Retevmo®)	Indicated as monotherapy for the treatment of metastatic RET fusion-positive non-small cell lung cancer (NSCLC) in adult patients	May 8, 2020	June 15, 2021	Final Recommendation April 28, 2022: Recommended pending cost-effectiveness	1 + 2
sotorasib (Lumakras®) 2nd line	For the treatment of adult patients with KRAS G12C-mutated locally advanced (not amenable to curative therapy) or metastatic NSCLC who have received at least one prior systemic therapy	May 28, 2021	September 10, 2021	Currently under review	2
tepotinib (Tepmetko®)	For treatment of adult patients with locally advanced unresectable or metastatic non-small cell lung cancer (NSCLC) harbouring mesenchymal-epithelial transition (MET) tyrosine kinase receptor exon 14 skipping alterations.	February 3, 2021	May 27, 2021	Final Recommendation August 24, 2022: Not Recommended	2

As of November 15, 2022 ALK = anaplastic lymphoma kinase CNS = central nervous system EGFR = epidermal growth factor receptor NSCLC = non-small cell lung cancer TKI = tyrosine kinase inhibitor

Table 2 — Date of Provincial Coverage

As of November 15, 2022

Drug Name	BC	AB	SK	MB	ON	QC	NS	NB	NL	PEI
alectinib (1 st and 2 nd line)	May 1, 2019	March 1, 2019	February 11, 2019	May 31, 2019	April 17, 2019	February 1, 2019	Oct 3, 2019	May 16, 2019	September 27, 2019	Not Funded
atezolizumab (2 nd line NSCLC)	November 1, 2019	October 7, 2019	February 11, 2019	February 13, 2019	December 6, 2019	February 1, 2019	Not Funded	October 30, 2019	Not Funded	Not Funded
bevacizumab (Mvasi)	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded
brigatinib (Alunbrig®) ALK-positive 1 st line	June 1, 2022	February 18, 2022	March 1, 2022	June 1, 2022	February 10, 2022	February 2, 2022	July 1, 2022	April 29, 2022	October 17, 2022	September 26, 2022
crizotinib (ROS1)	July 1, 2020	July 30, 2020	August 1, 2020	Not Funded	Not Funded	May 20, 2020	Not Funded	July 16, 2020	May 1, 2020	Not Funded
dabrafenib (Tafinlar®) & trametinib (Mekinist®)	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded
durvalumab (Imfinzi®) (1 st line NSCLC)	February 1, 2020	April 10, 2020	January 1, 2020	December 11, 2019	January 22, 2020	October 2, 2019	January 28, 2020	March 20, 2020	May 14, 2020	September 1, 2020
durvalumab (Imfinzi) 1 st line ES-SCLC	October 1, 2022	June 15, 2022	July 6, 2022	July 20, 2022	July 22, 2022	July 6, 2022	July 20, 2022	August 3, 2022	October 1, 2022	Not funded
entrectinib (Rozlytrek®) ROS 1	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	November 4, 2020	Not Funded	Not Funded	Not Funded	Not Funded
larotrectinib (Vitrakvi®)	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded
nivolumab - ipilimumab (Opdivo - Yervoy®)	May 1, 2022	April 1, 2022	May 1, 2022	April 1, 2022	June 17, 2022	November 9, 2022	August 1, 2022	June 23, 2022	June 1, 2022	Not Funded
nivolumab - ipilimumab MPM	May 1, 2022	April 1, 2022	May 1, 2022	April 1, 2022	June 7, 2022	March 2, 2022	August 1, 2022	June 23, 2022	June 1, 2022	Not Funded
osimertinib (1 st line)	January 1, 2020	April 10, 2020	March 1, 2020	April 2, 2020	January 10, 2020	December 18, 2019	May 1, 2020	March 19, 2020	February 20, 2020	February 14, 2022
osimertinib (2 nd line)	October 1, 2018	November 20, 2018	November 1, 2018	October 18, 2018	October 3, 2018	November 7, 2018	November 1, 2019	February 27, 2019	February 20, 2020	April 1, 2020
osimertinib (adjuvant)	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	November 9, 2022	Not Funded	Not Funded	Not Funded	Not Funded
pembrolizumab squamous NSCLC	June 1, 2020	September 15, 2020	May 1, 2020	April 30, 2020	June 10, 2020	September 11, 2019	May 1, 2020	July 16, 2020	June 1, 2020	Not Funded
pembrolizumab non- squamous NSCLC	June 1, 2020	September 15, 2020	May 1, 2020	May 1, 2020	April 24, 2020	April 8, 2020	May 1, 2020	July 16, 2020	June 1, 2020	January 2022
tepotinib (Tepmetko®)	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded	Not Funded

Table 3 — Number of Days from Date of FDA Approval to Date of Provincial Coverage

As of November 15, 2022

DRUG Generic name	FDA APPROVAL DATE	BC	AB	SK	MB	ON	QC	NS	NB	NL	PEI
alectinib (1 st line)	November 6, 2017	541	480	462	571	527	452	696	556	690	Not Funded
atezolizumab 2 nd line	October 18, 2016	1,109	1,084	846	848	1,144	836	Not Funded	1,107	Not Funded	Not Funded
bevacizumab (Mvasi)	September 14, 2017	778	Not Funded	865	739	704	Not Funded				
brigatinib (Alunbrig®) 1 st line	May 22, 2020	742	639	650	742	631	621	772	709	880	859
crizotinib (ROS1)	March 11, 2016	1573	1602	1,604	Not Funded	Not Funded	1,706	Not Funded	1,588	1,512	Not Funded
dabrafenib (Tafinlar®) & trametinib (Mekinist®)	June 22, 2017	Not Funded									
durvalumab 1 st line NSCLC	February 16, 2018	715	784	684	663	705	593	715	763	818	928
durvalumab 1 st line ES-SCLC	March 30, 2020	915	807	828	842	844	828	842	856	915	Not funded
entrectinib (ROS1)	May 5, 2020	696	637	Not Funded	Not Funded	Not Funded	471	Not Funded	Not Funded	Not Funded	Not Funded
larotrectinib (Vitrakvi®)	November 26, 2018	Not Funded									
nivolumab - ipilimumab (Opdivo - Yervoy®)	May 26, 2020	705	675	705	675	752	898	797	758	736	Not Funded
nivolumab - ipilimumab MPM	May 26, 2020	705	675	705	675	742	645	797	758	736	Not Funded
osimertinib (1 st line)	April 18, 2018	623	723	683	715	632	609	744	701	673	1398
osimertinib (2 nd line)	November 13, 2015	1,053	1,103	1,084	1,070	1,055	1,090	1449	1,202	1,560	1,601
osimertinib (adjuvant)	December 18, 2020	Not Funded	691	Not Funded	Not Funded	Not Funded	Not Funded				
pembrolizumab squamous	October 30, 2018	651	757	620	619	589	316	620	696	651	Not funded
pembrolizumab non-squamous	August 20, 2018	651	757	620	620	613	597	620	696	651	1230
tepotinib (Tepmetko®)	February 3, 2021	Not Funded									



Conclusion

Afterword: *What* have we done for people living with lung cancer?

Shem Singh, Executive Director

Throughout this report, our aim has been to put the faces of lung cancer front and centre – people living with the disease, their caregivers and loved ones, and the wider community working to improve treatment and outcomes.

I am reminded of something that Ralph Gouda, one of LCC's founders, asked me when we first met, something I ask myself every day: "What have we done for a lung cancer patient today?"

A simple but brilliant reminder of the "who, why, and what" of Lung Cancer Canada.

Both Dr. Snow and Dr. Wheatley-Price have described *who* we are and *why* we exist. Finally, here is some of *what* our small but nimble charity has done for lung cancer patients in the past 12 months:

THE 2021 AND 2022 EVENING OF HOPE

had the highest ever participation from people living with lung cancer across Canada, and raised the most funding for LCC's patient supports.

We helped patients with practical support such as parking passes, taxi trips, and other needed vouchers through

KAYLA'S ANGEL FUND

THE GEOFFREY OGRAM MEMORIAL RESEARCH GRANT

provided two awards in 2022 to help advance knowledge about lung cancer.

OUR PEER2PEER SUPPORT NETWORK

now offers more one-on-one support than ever.

OUR NEWLY ESTABLISHED LUNG AMBITION AWARDS

will provide up to two grants each year for the next three years.

WITH THE LUNG HEALTH FOUNDATION

we took on stigma with a campaign called "Stop Asking the Wrong Question".

OUR PATIENT GUIDE

a cornerstone of the support we offer, is now more widely available across the country in more different languages to meet the needs of people living with lung cancer.

LCC established several

PATIENT-LED SUPPORT HUBS

in Western Canada.

STAKEHOLDER BRIEFING

had the largest and most diverse audience ever in 2021.

OUR NEW AIRWAYS OF HOPE PROGRAM

has made a registered social worker available for support and engagement.

Our submissions to

CADTH AND INESSS

with patient and clinician input is strong advocacy for public reimbursement of lung cancer treatments, and we have done more than ever.

OUR PODCASTS AND WEBINARS

which are attracting more and more people, make information about lung cancer widely available to everyone in Canada, with a French-language series soon to come.

We've supported the EXCEL PROGRAM

where lung cancer patients can receive physical and mental wellness sessions, both virtually and in-person.

Expanded our library of

PATIENT STORIES

and presented a three-part video series on social media focusing on the reality of lung cancer with Hope Army.

TWO IN-PERSON EVENTS

in Vancouver and in Montreal (en français, une première pour Cancer Pulmonaire Canada!)

PARTNERING WITH GIVE A BREATH 5K

a well-established local charitable fundraising event that we aim to take nationwide and establish as THE lung cancer fundraising event in Canada. A wonderful partnership that has already generated funds to sustain the Airways of Hope program for another year.

I would be remiss if I did not express my gratitude for the hundreds of volunteers who have collectively contributed thousands of hours towards supporting Lung Cancer Canada. I am immensely proud to say that, as an organization, we have become stronger. Our capacity and reach continues to grow year over year, and we look forward to the future with HOPE for all lung cancer patients nationwide.



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PHOTO CREDITS

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Tim Monds

Leon D'Silva

Jacques Morand

Chantal Brunet

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Lung Cancer Canada is a national charity and the only one dedicated solely to lung cancer. It relies on donations to offer programs and services, such as this booklet, to patients and their families.

Donations are greatly appreciated and a tax receipt is issued for a donation of \$20 or more. Donations can be made online at www.lungcancercanada.ca, or by calling the numbers above.

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