



LOOKING FORWARD AND THE YEAR IN REVIEW:

Dr Paul Wheatley-Price, President, Lung Cancer Canada



Dr Paul Wheatley-Price, President, Lung Cancer Canada, BSc, MBChB, FRCP (UK), MD

A few years ago, I listened to “Start With Why”, a TED talk by Simon Sinek, which contained a message that has resonated with me ever since. Sinek explains that there are three perspectives that define an organization: why they do what they do, how they approach it, and finally what they actually do. He maintains that many organizations are very good at the “what” and “how”, but the truly exceptional and successful organizations start with “why”. “How” and “what” then flow from that core reason.

Why does Lung Cancer Canada (LCC) exist? It is because lung cancer remains the number one cancer in Canada for all the wrong reasons. It is the most commonly diagnosed, the unfortunate leader of the big four (lung, prostate, breast and colorectal). It is the number one cancer killer, exceeding those other three combined. It remains the most deadly cancer

among women; it remains underfunded for research and it remains a disease laden with stigma.

That is why we exist, to educate, to raise awareness and to support patients and families with lung cancer across Canada in all provinces and territories. There is no other national lung cancer organization in our country, so that is why we are here. What we do and how we do it – our programs, materials, initiatives and advocacy stem from that core “why”.

Last year was a banner year for lung cancer. The global community was in Toronto in September 2018 for the World Conference on Lung Cancer. LCC had a significant presence. New research findings showed promise: confirming that lung cancer screening with low-dose CT scans has a huge potential to save lives, that immunotherapy can be effective in more lung cancer patients and situations, and that new targeted therapies are emerging for sub-groups of lung cancer. Patients across the country made LCC’s booth a meeting place to connect and exchange conference notes.

At LCC, our Patient Guide is the essential resource for lung cancer patients and caregivers. At the end of 2017, we released a new version and distributed over 14,000 copies in 2018.

We worked harder than ever to advocate for access to new and effective treatments. We have seen groups in multiple provinces lead initiatives: patient support groups, expansions of our Peer-to-Peer network, and patient summits. We released the Faces of Lung Cancer report in November and the Calendar of Hope, and we have had an unprecedented number of meetings with provincial and federal politicians. In 2018, we saw successful

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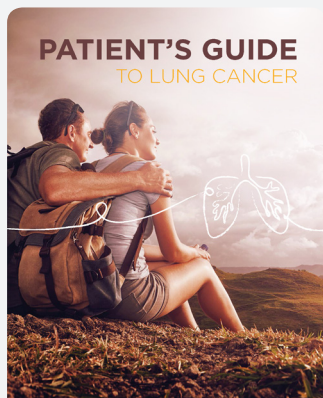
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PATIENT RESOURCES



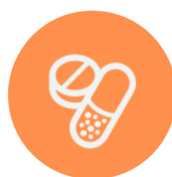
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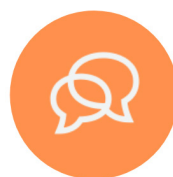
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NEW TREATMENT HORIZONS

by Dr Rosalyn Juergens, Chair, Medical Advisory Committee,
Lung Cancer Canada

Going back just 10 years, there were a limited number of options for treating non-small cell lung cancer (NSCLC). For the vast majority of patients, the treatment options started with chemotherapy combinations followed by more chemotherapy if the first line of treatment failed. Only a small minority of patients could get personalized treatments. Today, however, due to major advances, the treatment landscape has changed. Immunotherapy is now a potential treatment for the majority of patients with lung cancer and we have more patients on targeted therapy. Even those patients who were on targeted therapy a few years ago now have more options available. Unlike years ago, we can now prioritize a patient's treatment journey to offer the best treatment as early as possible.

Although statistics from the Canadian Cancer Society continue to show disappointing survival metrics with the diagnosis of lung cancer, improvements will become evident in the upcoming years. While it is fantastic that we are expanding the amount of time people are living with lung cancer, it is also equally important to ensure patients have a good quality of life while receiving those treatments. New treatments recently approved have shown improvements in patient's quality of life as well as survival compared to the standard comparators. Better treatment quantity and quality are fortunately going hand in hand.

Some of the most excitement in 2018 was generated through advancements in the management of stage III non-small cell lung cancer. With the addition of immunotherapy consolidation to standard chemotherapy and radiation, we already know we are extending lives. We hope that further follow up data will show that we are truly curing more of these patients.

Also gaining momentum are early screening programs, as seen with the pilot programs in Ontario. If physicians can diagnose patients at stage I versus stage IV, the chances of patients living longer is vastly improved and the probability of being cured is higher. Reflecting on the NELSON Study presented at the 2018 IASLC World Conference for Lung Cancer, with such screening programs in place for high risk patients, more cases are diagnosed in early stages when surgery is often an option. Screening also shifts the pendulum by diagnosing patients earlier, leaving fewer cases diagnosed in advanced and incurable stages.



Dr Rosalyn Juergens,
Chair of Medical
Advisory Committee,
Lung Cancer Canada,
B.S. (Hons), MD., PhD

Additionally, we also cannot underscore the importance of smoking cessation and smoking avoidance. It is important for screening programs to go hand in hand with smoking cessation programs. Everyone with lungs needs to be mindful of exposures and keeping optimal lung health!

My hope for the future of lung cancer is a world where medical oncologists, like me, are out of business. We need to identify an optimal way to screen. While the current screening method is through CT scanning in high-risk populations, I hope patients in the future can be screened through other means such as blood or breath tests through which we can discern patients at risk for future lung cancer. I hope that there will come a day when physicians can diagnose all patients at an early stage when a localized approach can result in a cure. Until then, understanding the tumor to personalize treatment options is critically important. Comprehensive and timely genetic profiling allows patients to move forward with the optimal treatment as the first choice.

In Canada, health care access is largely universal, but it is also a patchwork quilt in terms of provincial access. I hope for equity across the provinces because, depending on where you live, access to advances or new treatments may be limited. The waiting time for access to new drugs could be time many lung cancer patients do not have. With the support of Lung Cancer Canada we will continue to strive to attain the same opportunity to access approved treatments across the country so lung cancer patients can live longer with a better quality of life. 🌱

PATIENT STORY

10 YEARS OF LIVING WITH STAGE IV LUNG CANCER

By Anne Marie Cerato

As I write this article, I sit here reflecting on how best I could describe my last ten years. It would be easy to say that I have changed physically and of course, I am older, but it isn't just that. Literally everything in my life has changed.

What is a decade after all? It could be 120 months, or 520 weeks, 3,650 days, 87,600 hours, or 5,256,000 minutes.

For me it has been a quarter of my life, but it seems like a lifetime.

I could never have predicted that I would still be here today to write this, ten years ago, when everything seemed so up in the air and terrifying.

I have come along way, and so have things in the lung cancer world. In these past ten years, there has been unprecedented success in lung cancer research resulting in 20 new breakthrough drugs. I wouldn't be here if it weren't for them.

gratitude

noun

grat-i-tude\ 'gra-ta-, -tyüd\

Definition of gratitude : the state of being grateful :

THANKFULNESS

//expressed gratitude for their support

To simply express my gratitude using this definition would be wholly insufficient. In fact, there aren't enough nouns to express what it means to have been given the gift of ten years of life.

April 15, 2019 will mark a decade since I was first diagnosed with advanced lung cancer. It's a pretty huge milestone for all the wrong but truly miraculous reasons. At the time of my diagnosis, I was in the last few months of my thirtieth year, completely unaware of the maelstrom about to hit me. It wasn't as if I had any glaring symptoms to indicate I was sick, just some vague nuisances that I passed off as being tired and run down from working. How wrong I was. What started as a small lump on my collarbone became stage IIIA Adenocarcinoma,



Anne Marie Cerato, Board Member and Patient Advocate, Lung Cancer Canada

and later stage IV advanced ALK+ NSCLC, into the abyss I fell. I have been falling ever since.

I could say I was falling, but in reality, I am flying.

Anyone looking in on my life BC (Before Cancer) would have thought I had it all. I had my dream job, virtually no expenses, and I was free to do as I pleased. For all intents and purposes, I was on the typical life trajectory. Upon closer inspection, what you would have seen however was something entirely different. I was so busy trying to be everything to everyone, that I had nothing left for myself. My relationships suffered, I was painfully lonely and single, and all I did was work.

CANCER CHANGED EVERYTHING!

After diagnosis (AD), it was as if the veil that clouded my eyes was lifted. Colours were more vibrant, mundane things beautiful, I made different priorities and I chose to live. What I mean by that, is to live without regret, to live authentically, to be present in my life, and to experience life and all it has to offer. Choosing

AN OVERVIEW OF CANADA'S DRUG APPROVAL AND ACCESS PROCESS

Quite often, we are asked how drugs are approved. In Canada, there is a systematic process carried out by several entities to determine and ensure the safety, efficacy and prices of drugs before they are available to the public.

Here is a brief summary:

- The drug manufacturer submits a New Drug Submission (NDS) to Health Canada (1) for review and approval. This submission contains scientific data on the drug's safety, efficacy and quality, results of preclinical and clinical trials, the therapeutic uses and side effects. This data is evaluated to determine the potential risks and benefits.
- If Health Canada determines the benefits outweigh the risks, it officially approves the drug for sale, and the manufacturer receives a Notice of Compliance (NOC) or Notice of Conditional Compliance (NOC/c) and a Drug Identification Number (DIN). An NOC/c is authorization to market a drug with the condition that the manufacturer undertake additional studies to verify the clinical benefits.
- At this point, physicians can prescribe the drug, however, it would be paid for out-of-pocket or through private health care plans.
- Once approved, the Common Drug Review (CDR) (2) and the pan-Canadian Oncology Drug Review (pCODR) (2), administered by the Canadian Agency for Drugs and Technologies in Health (CADTH) will assess the data to determine the drugs eligibility for public reimbursement. In Québec, the National Institute of Excellence in Health and Social Services (INESSS) (2) carries out this role. Expert panels review the clinical evidence, cost-effectiveness, and patient and clinician perspectives. The new drug is also compared to existing drugs already on the market. With a positive recommendation, the next step is for drug programs to begin negotiating pricing with the manufacturer.
- The pan-Canadian Pharmaceutical Alliance (pCPA) (3) conducts joint provincial, territorial and federal negotiations to help achieve better value for publicly funded drug programs and patients by combining the negotiating power of participating jurisdictions. This helps reduce duplication, and provides consistency in terms of decisions and cost effectiveness.
- One jurisdiction will assume the lead on the negotiations with the manufacturer, and a letter of intent is signed when an agreement has been reached. It is then up to the participating jurisdictions to determine when to list it on their publicly funded formulary.
- The Executive Officer of drug programs at each provincial Ministry of Health (4) receives this letter of intent and makes the final decision based on its committee's recommendation, funding availability and the best interest of the public.
- This drug approval process though extensive, aims to provide a thorough and objective evaluation of the submitted drugs, consistency in pricing, and ensure and improve access to clinically effective and cost-effective drug options. 🌱



Drug Approval and Access Process in Canada

2018 FACES OF LUNG CANCER REPORT (FOLCR)



2018 Faces of Lung Cancer Report

The 2018 Lung Cancer Canada Faces of Lung Cancer Report (FOLCR), Achievements, Driven by Hope highlights the remarkable achievements in the fight against lung cancer and also provides a glimpse of the current state of lung cancer in Canada and what the future holds.

#HOPE IS HERE. While there is still a lot of work to accomplish in the management of lung cancer, which has just a 17% survivorship rate, some progress that is encouraging has been achieved. With innovations in recent years, patients are able to live longer, have a better quality of life, spend time with their loved ones, and even hope for the future.

#HOPE IN SCREENING. Screening save lives! Lung cancer kills more than 21,000 Canadians every year and with early detection through screening, long-term survival rates will improve. With early diagnosis, curative treatment is possible thus giving patients a greater chance of survival.

#HOPE FOR THE FUTURE. New data suggests that the new treatments available are improving quality of life

and longevity of lung cancer patients. At the World Conference on Lung Cancer, which was held in Toronto last September, a number of studies were presented by the experts, which showed improved survival rates for lung cancer patients living with Stage IV lung cancer. Treatment advances that improve survival rates in earlier stages are also becoming available.

Though much has been achieved, there is still a lot to do. As you will see from the report, access to treatment differs between provinces and there are large gaps of time between Health Canada approval and provincial funding. Let us work together to fight this devastating disease, towards a better future, giving patients and their loved ones hope.

The full report is available at www.lungcancercanada.ca. 🌱

#HOPE IS HERE, #HOPE IN SCREENING, #HOPE FOR THE FUTURE.

EVENTS FOR HOPE

Convoy for Hope – Atlantic

Despite the wet weather on August 18, 2018, the Convoy for Hope - Atlantic had a great turnout. 25 registered trucks, 4 corporate sponsored vehicles, 24 CAV and support units, and a wonderful supportive community came out in Moncton, NB in support for cancer. They raised \$9,000.00 for Lung Cancer Canada. This annual celebration of the trucking community was established to create awareness, promote early detection, and to raise funds in the fight against the top four cancers affecting Atlantic Canadians. Thank you Atlantic Canada!

<http://convoyforhope-atlantic.com/>. 🌱



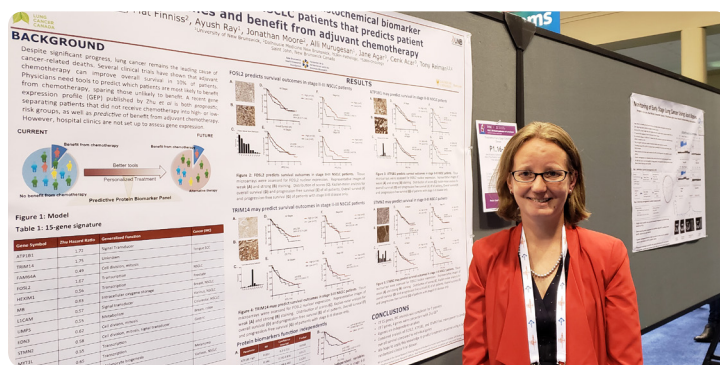
The Convoy for Hope has been donating to lung cancer for the past five years.

World Conference on Lung Cancer, 2018 Report by Stacy Grieve

In the spirit of fostering the next generation of lung cancer researchers in Atlantic Canada, part of the funds raised by the Convoy of Hope Atlantic was used to send one of their own, Stacy Grieve to attend the World Conference on Lung Cancer in Toronto. See Stacy's story below:

Thanks to Lung Cancer Canada, I attended the WCLC in Toronto, ON from September 23-26th. This was my first time attending a meeting put on by IASLC and it was an excellent experience. I found the conference very clinical in nature, with an emphasis on new treatments, particularly immunotherapy, and new ways to monitor the disease. As a cancer cell biologist, I generally spend my days learning about specific genes and how they affect cancer cell growth and response to treatments; it's refreshing to get out of the lab and hear how, collectively, our research is improving lives.

I also was pleasantly surprised by the role that patient advocates played in the conference, even with specific sessions geared towards them. The highlight of the conference was listening to the eloquent words and encouraging message spoken by Lucy Kalanithi at the opening plenary session. I presented



Stacy Grieve at the World Conference on Lung Cancer in Toronto

my research during the poster session on the 24th. Not only did I have people stop by because they were excited to see someone from New Brunswick, but I also had a couple of interesting conversations about the methodology I am using.

Scientifically, I took away two key messages from the conferences: firstly, the importance of immunotherapy; and secondly, the potential of liquid biopsies. These are ideas I will move into my research. So thank you, again, for the opportunity to attend this conference. 🌱



Dr N Leighl, Dr A Bezjak, Dr G Darling, Co-Presidents of the 2019 IASLC WCLC

IASLC World Conference for Lung Cancer

The International Association for the Study of Lung Cancer World Lung Conference 2018 took place at the Metro Toronto Convention Centre from September 23-29, 2018. It was the world's largest international gathering of clinicians, researchers and scientists in the field of lung cancer and thoracic oncology, with delegates from more than 100 countries attending. Lung Cancer Canada's past-president Dr Natasha Leighl was one of the co-presidents for the conference. <http://wclc2018.iaslc.org>. 🌱



IASLC-LCC Walk Participants

International Association for the Study of Lung Cancer – Lung Cancer Canada (IASLC-LCC) Walk

It was a beautiful morning for the IASLC-LCC Awareness Walk on September 23, 2018 at 8:00 am. There were 164 registrants for this guided 3km walk from the Metro Toronto Convention Centre to the Toronto lakefront to promote awareness of lung cancer and kick off the IASLC World Conference. Thank you to all walkers for getting up so early on a Sunday morning to help us increase awareness for lung cancer. 🌱

Scotiabank Toronto Waterfront Marathon

Thank you to the 20 participants who raised \$12,943 for Lung Cancer Canada at The Annual Scotiabank Marathon on October 21, 2018 despite the chilly temperatures! This fast, fun and family friendly event has 5k, Half-Marathon, and Marathon lengths and can be walked as well. Please join us this year on Sunday October 20, 2019! Register today at: <http://www.torontowaterfrontmarathon.com>. 🌱



Yolande and **Brett Northrup**



Dr Stephen Lam presenting the NELSON study results at the stakeholder briefing

Lung Cancer Canada Stakeholder Briefing

Lung Cancer Canada held its annual stakeholder briefing at the Ivey Tangerine Leadership Centre on Tuesday, November 13th, 2018 to celebrate Lung Cancer Awareness Month. The theme was Achievement of Hope, speakers included Dr Paul Wheatley-Price, Dr Rosalyn Juergens and Dr Stephen Lam. 🌱

Elizabeth Denis Dessureault Memorial Hockey Tournament

Cornwall, Ontario came out in support of Lung Cancer Canada and in memory of Elizabeth on Sept 29 – 30, 2018. Eleven teams took part in three divisions and raised \$7,000! Elizabeth passed away from lung cancer, but her memory is honored with the Elizabeth Denis Dessureault Memorial Hockey Tournament to raise money to help fight lung cancer. 🌱



Dropping the Puck at the Elizabeth Denis Dessureault Hockey Tournament

Ottawa Regional Patient Summit

Ottawa was host to a lung cancer mini-summit, which took place at the Ottawa Hospital on November 27th, 2018. "Living with Lung Cancer" was an empowering, patient-driven event featuring presentations from patients, caregivers, clinicians and psychosocial oncology. We hope to take this model and hold several more across the country this year! 🌱



Ottawa Regional Patient Summit

The Evening of Hope

The 8th annual Evening of Hope took place on Thursday, November 29, 2018. Over \$80,000 was raised to help educate, empower and support lung cancer patients! Thank you to all of our dedicated volunteers and renowned guest speaker, Dr Raymond Laflamme, who made this very special night possible! Additionally, much appreciation to the very generous donors and sponsors – we look forward to seeing you all again in 2019! Thank you for your continued support of LCC. 🌱



CREDIT: Bill Johnston Photography

2018 Lung Cancer Canada Evening of Hope

Calgary Lung Cancer Awareness Day

On November 29th, 2018, the Alberta Thoracic Oncology Program held an awareness day. This event is a wonderful example of the activities that were held across the country for Lung Cancer Awareness Month. Thank you to all of our fantastic volunteers! 🌱

Lung Cancer Awareness Day,
Tom Baker Cancer Centre



Makeup for Lung Cancer

With several events occurring throughout the year, including a Golf Tournament and sponsored nights at Boston Pizza and Indigo, Michelle Brennan raised over \$11,600 for LCC! Thank

you Michelle, for your amazing fundraising and advocacy activities. 🌱

LOOKING FORWARD!

2019 EVENTS FOR HOPE

On February 20, 2019, Lung Cancer Canada partnered with the Canadian Cancer Survivor Network (CCSN) to host the Right2Survive event. At the event, which took place at Queen's Park, lung cancer patients, survivors and advocates had the opportunity to meet with their MPP's to discuss issues such as lung cancer research and access to treatments for lung cancer patients. Anne Marie Cerato, a 10-year lung cancer survivor spoke about the importance of access to early screening and treatments. 🌱



Anne Marie Cerato



Health Minister Christine Elliot with lung cancer advocates

CREDIT: Jay Gundu - Jag Photography

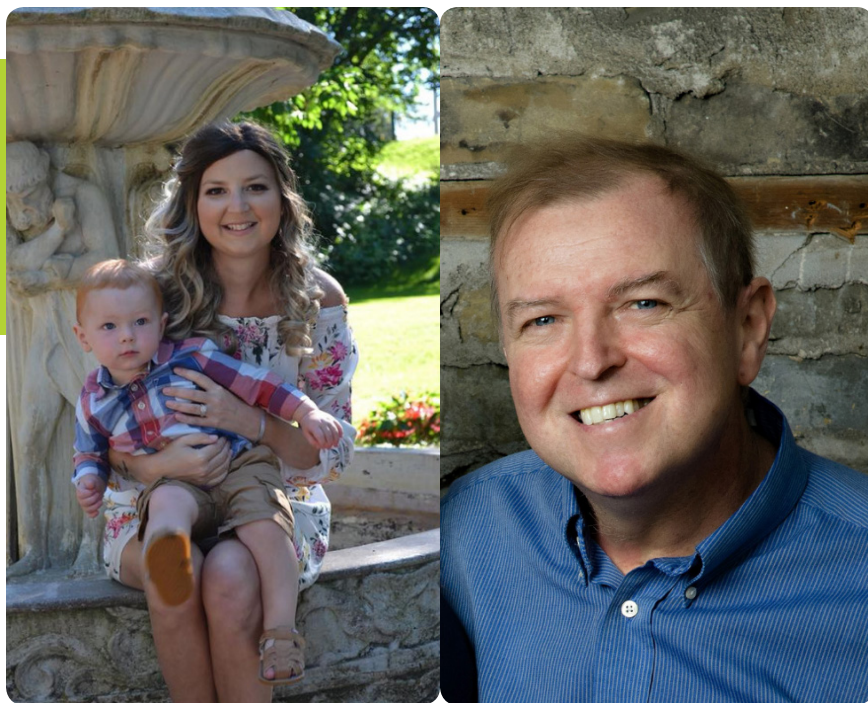
CREDIT: Minister of Health and Long-Term Care Staff

UPCOMING EVENTS IN 2019

- Kayla's Fight Club Casino Night – March 25th, Crazy Horse Bar and Grill, Kanata, ON
- Ottawa Lung Cancer Awareness Day on Parliament Hill – Spring 2019
- Tamarack Ottawa Race Weekend – May 25th & 26th, Ottawa, ON
- Makeup for Lung Cancer Annual Golf Tournament – June 14th Canadian Golf and Country Club, Ashton, ON
- Casey Cosgrove Golf Tournament – July 19th, Hidden Lake Golf Club, Burlington, ON
- Scotiabank Toronto Waterfront Marathon – October 20th
- Lung Cancer Canada Annual Stakeholder Briefing – November, Toronto, ON
- Evening of Hope – November, Toronto, ON
- Elizabeth Denis Dessureault Memorial Hockey Tournament... TBD
- Convoy for Hope – Atlantic... TBD
- Regional Patient Summits across Canada – Calgary, Montreal
- Geoff Ogram Memorial Research Fund – Applications will open Spring/ Summer 2019
- And more...

If you require further information about upcoming events you would like to attend or want to set up a similar event in your area, contact us at info@lungcancercanada.ca or call 416.785.3439 | 1.888.445.4403.

IN MEMORIAM



CREDIT: Heather MacEachern-Tarasick (HRM Photography)

Kayla MacWilliam (Bradford) and Dr Marcelo Kremenchutzky

TRIBUTE TO KAYLA MACWILLIAM (BRADFORD) AND DR MARCELO KREMENCHUTZKY

In 2018, Lung Cancer Canada lost two of our Ambassadors of Hope, Kayla MacWilliam (Bradford) and Dr Marcelo Kremenchutzky.

Kayla was 25 and her baby was just two months old when she was diagnosed with stage IV lung cancer. After the shock of, “I never thought it would happen to me,” Kayla went into fight mode and had the support of her Fight Club and family behind her. It was that fighting spirit and treatment advances that allowed her to celebrate her son Leighton’s first birthday, pick out his Christmas presents and marry her soulmate Jordan.

Marcelo was an internationally renowned neurologist that had cared for thousands of multiple sclerosis patients. He and his wife, Danine were focused on raising their twins. Being diagnosed with stage IV lung cancer suddenly turned the doctor in the patient. “Don’t be sorry – be hopeful”, said Marcelo. For him, it was about changing the energy of fear or sadness into something positive. Creating living milestones that lung cancer could never touch.

Both Marcelo and Kayla advocated tremendously for lung cancer awareness and generously shared their stories to improve services, improve access to medications and improve patient survival.

Although the journey has ended for Kayla and Marcelo – they did Achieve Hope.

Marcelo left us with this statement, “Many of us are under the impression that every day should just be good, when this is not the case at all. Life can be extraordinary. But we must anticipate and learn from the challenges – this is where we find the strength and hope to take it on.”

We draw from Kayla and Marcelo’s strength and we will continue to be the “Fight Club” for lung cancer patients and their families. 🌱

CONTINUED FROM PAGE 1

regional summits in Halifax and Ottawa, following on from the gathering at World Lung and previous larger events in Toronto and Vancouver. We also doubled the amount of fundraising events throughout the country!

In those meetings, we advance our main 3 points:

1. **Raising awareness**
2. **Promoting screening**
3. **Access to care**

What will 2019 bring, and how can you help? I am pleased to report that LCC is growing. We are soon to complete a governance restructuring and we continue to seek diversity in income and prudently use the dollars entrusted to us.

With that, outreach is of particular importance. We hope to be able to deliver multiple events across Canada to educate and raise awareness. Whether it is patient support, awareness or

fundraising event, if you would like to help us organize one in your area we need to hear from you.

In addition to the core programs we are known for, look out for a new LCC Podcast series and expansion of the peer-to-peer network. We are unwavering in our ongoing commitment to support Canadians with lung cancer everywhere. That will mean that we actively seek out opportunities from coast to coast. We will see increasing engagement with Provincial and Federal politicians, including a recently formed Senate group. Some of these will be led by LCC, others in partnership with other patient groups that have shared concerns. In particular, we are working on screening and access to care. We are particularly concerned about the high lung cancer rates among Inuit and First Nations, and we are trying to build partnerships to find solutions that will improve lung cancer outcomes.

Thank you for your continued support of our organization, and we hope we can count on you again in 2019. 🍀

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the philosophy of “more life to days rather than days to life,” has not steered me wrong so far. In fact, it has lead me to many unique and wonderful opportunities. I think for the most part humans, especially those of us under a certain age, believe we are invincible, at the least, we don't think too much on the state of our health, that is until it fails us. Then, everything we know gets called into question. That is exactly what happened to me. It could have been a stumbling block or an opportunity to rebuild something better. I chose the latter. In doing so, I have been privileged to meet and work with incredible people, travel the

world learning and advocating for a cause I am truly passionate about. I opened my heart to possibility and met the man I love, together we live in a house that I never thought I would have with two ridiculous dogs and two crazy cats. Together, we follow our dreams, we pursue our passions, we live in today with the hope of tomorrow. We dream.

None of it could be possible without the love of our families, the support of friends, and the wonderful care I have received and continue to receive. 🍀

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You Can Help Make a Difference

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Address: _____

Phone: _____

Email: _____

(for future communications)

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Thank you! Tax receipts will be issued for donations of \$20.00 or more. Charitable Registration #872775119RR0001

To donate online, visit www.lungcancercanada.ca.

Tribute and monthly gifts may also be made online or by phone at **416.785.3439** | **1.888.445.4403**.

☐ My cheque payable to **Lung Cancer Canada** is enclosed. **OR**

☐ Please charge my: ☐ VISA ☐ MasterCard

Card Number: _____

Exp Date: _____

Cardholder's Name: _____

(please print)

Signature: _____



**LUNG
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