

lung
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starts
now



lung health
foundation

From Ontario Lung Association to Lung Health Foundation:

Lung Health Starts Now!



ANNUAL REPORT 2019/20

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Financials

We value the investment our donors and supporters make with us. We work hard to ensure that the funds we receive directly benefit our frontline programs and services and critical research initiatives, all with the end goal of helping Canadians improve their lung health. To view our audited financial statements, visit lunghealth.ca/annualreports.

Ontario Lung Association is a registered charity operating as the Lung Health Foundation.

Visit us online at lunghealth.ca.



A message from our Board Chair and CEO

It is our privilege to present this year's Annual Report — our first since becoming the Lung Health Foundation.

In this report, you will read about some of the highlights of our transformative 2019/20 year. You will also catch a glimpse of the exciting changes to come as we prepare for the launch of a new strategic plan that will allow us to better serve the 1-in-5 Canadians affected by lung disease.

This year, we invested \$1,321,025 in ground-breaking respiratory research. From gene therapy that unlocks survival for critically-ill newborns to discoveries that could prevent deaths from post-pneumonia complications, our researchers worked to fill knowledge gaps and create solutions that will help Canadians beat lung disease from birth to our twilight years. In this report, you'll learn about two of the incredible chronic obstructive pulmonary disease (COPD) studies funded last year, each with a different approach to saving lives. Our impact will continue to grow in 2021 thanks to exciting changes coming to our research program.

We have driven and continue to push for important policy changes to improve the lives of those affected by lung disease. Through our Breathing Policy Forum series, we brought together experts to explore some of the most urgent and pressing issues facing health-care today, like breaking down the barriers that stand in the way of vaccine innovation — work that feels all the more critical in current times.

In February, we re-introduced ourselves to the world as the Lung Health Foundation. With a new name and brand that put the urgency of lung health front and centre, we began charting a new path forward.

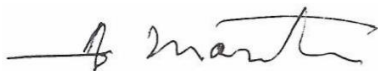
And then, in the late stages of our 2019/20 fiscal year, the world was introduced to a new lung health threat: COVID-19.

The pandemic hit as our new brand was in its infancy, and it highlighted the importance of respiratory health in unprecedented ways.

When Canadians affected by lung disease had questions about staying safe, the Lung Health Foundation's team of Certified Respiratory Educators had answers. When Canadians needed support in increasingly uncertain times, the Lung Health Foundation was there with new initiatives that filled gaps in psychosocial support. We are especially proud of the work we did to help chronic lung disease patients prevent flare-ups that could have sent them into the crowded hospital system. That work continues today.

Last year, your support made it possible for the Lung Health Foundation to deliver on our mission of improving the lung health of Canadians. Lung health starts now, thanks to you.

Sincerely,



John Martin
Board Chair
Lung Health Foundation



George Habib
President & CEO
Lung Health Foundation

A New Name. A Renewed Mission.

As the Ontario Lung Association, we worked tirelessly to be the recognized leader, voice and primary resource in lung health. Meanwhile, lung disease continued to place a profound burden on patients and their families, and it placed a large (and growing) economic burden on every provincial health-care system across Canada.

It was time for a new approach.

During a year rich in programming and research investments, our team worked behind the scenes to bring the Lung Health Foundation to life.

We are confident that our greatest accomplishment in 2019/20 — the birth of our new brand and new approach to tackling lung disease — will have an impact for years to come.

Our Vision

A world where everyone can breathe easier

Our Mission

Improving the lung health of Canadians

Our New Areas of Focus

Along with our new brand, we unveiled our new areas of focus in 2019/20. Today, we help Canadians manage their health and well-being through our focus on:



Asthma

We're working to ensure that no one loses a loved one to asthma.

Key 2019/20 moment: We launched six new pediatric inhaler videos to help families prevent attacks and keep asthma controlled. Since launch, they've been viewed 6,000 times!



Chronic obstructive pulmonary disease

We offer COPD patients programs and resources to keep them out of hospital, so they can live their lives to the fullest.

Key 2019/20 moment: We unveiled Helping the Missing Million, a national study report that highlights significant diagnosis and care gaps. Turn to page 9 to see the policy change solutions that will help us catch this progressive disease as early as possible.



Lung cancer

We're eliminating the barrier of stigma and giving those living with lung cancer a fighting chance.

Key 2019/20 moment: We published Coping with Lung Cancer, an empowering new resource that is helping Canadians navigate everything from diagnosis to end-of-life decision-making.



Immunization:

We work to ensure that older adults have access to the vaccinations they need to stay healthy and maintain their independence.

Key 2019/20 moment: We launched the Adult Immunization Card, an easy-to-use tool that keeps track of vaccines, including lung-protecting immunizations against influenza and pneumococcal pneumonia.



Smoking/Vaping Prevention and Cessation

We provide support and education to ensure that future generations don't suffer the debilitating effects of lung disease caused by tobacco, cannabis, or vape products.

Key 2019/20 moment: A not-so-super hero crash-landed on university campuses from coast-to-coast to spread the word on respiratory risks of inhaled cannabis products. Read more about the Toker campaign on page 14.

While we will be focusing our efforts going forward, the Lung Health Foundation continues to serve Canadians affected by any form of lung disease through initiatives like our Lung Health Line, support groups, and Fitness for Breath programs.

Coming Soon – A New Strategic Plan for a New Era

With our new strategic plan, the Lung Health Foundation will adopt a uniquely integrated approach to improving the lung health of Canadians by identifying gaps and addressing them through:



Concentrating our efforts in **asthma, chronic obstructive pulmonary disease, and lung cancer**, as well as key areas affecting lung health such as immunization, smoking/vaping prevention and cessation, and access to medications/treatments



Modernizing our **research program**, broadening its scope, and better aligning it with our organizational priorities



Driving **policy** and **practice change**



Investing in urgently needed **programming** and **supports**



Promoting **awareness** about the lung health issues affecting everyone

With a more clear and defined focus, everything we do will work toward the changes we need – from research and knowledge translation, to awareness and education, to direct programming and patient support, to advocacy and policy change.

Research Spotlight: Reducing the Severity of COPD

“My research will have an impact on lung health by allowing us to understand how the genetics of an individual impact their susceptibility to different lung diseases.”

Dr. Simon Sharpe

*Senior Scientist and Associate Professor of
Molecular Medicine, University of Toronto*

Severe chronic obstructive pulmonary disease (COPD) means more than just shortness of breath. Compared to someone with a mild case, the body of a person with severe COPD may be unable to repair damaged lung tissue, or could be more susceptible to developing that damage in the first place. While this damage is mostly caused by external factors like a person's environment or a history of smoking, recent evidence points to internal factors that could affect a person's predisposition to ever developing this disease.

In other words, one individual may be fine, while another in the same environment develops severe COPD, and the reason may be something that's happening at the cellular level. Thanks to funding from the Lung Health Foundation, Dr. Simon Sharpe is investigating why this is the case and what role elastin plays.

Elastin is the main protein that forms the elasticity (stretchiness) in your arteries, skin, bladder, and lungs. It assembles outside of the cells, and allows your tissues to stretch and contract. What if small defects in the way your elastin was assembled made it weaker and less stretchy, or made it fail prematurely? With a less stable elastic matrix, your body would be less successful at repairing lung tissue damage.

By modeling the elastic tissues of the lung, Dr. Sharpe and his team at The Hospital for Sick Children are trying to understand how the gene sequences of specific individuals impact their body's ability to produce the kind of elastic tissue that will last an entire lifetime.

In the long term, Dr. Sharpe hopes to use his team's findings to identify new preventative or therapeutic strategies so that fewer people suffer from severe COPD. Imagine how life-changing that would be.

National Study Spotlight: Who are the Missing Million?

“Uncovering barriers to diagnosing COPD will help us better understand how we can care for patients.”

Dr. Andrea Gershon
Respiratory Physician & Scientist, Sunnybrook Research
Institute and ICES (Institute for Clinical Evaluative Sciences)

“I had very little knowledge of COPD or how serious it was when I started on my journey, which created challenges when it came to being diagnosed and getting on the right treatment. It’s so important for people at-risk of this disease to promptly seek out medical advice, educate themselves about the symptoms and work closely with their health-care team to make sure they can be properly diagnosed and treated as quickly as possible.”

Barbara Moore, patient & advocate

Approximately two million Canadians live with COPD, but as many as one million more may be living with this disease *without even knowing it*. These patients are often left undiagnosed and untreated while their symptoms worsen. Our pan-Canadian *Helping the Missing Million* research project set out to better understand why Canadians aren’t getting diagnosed sooner, and find out whether they are accessing the best treatments once diagnosed.

In October, the Lung Health Foundation released the findings of this research in a policy paper that outlines the five core policy and practice change recommendations coming out of this study:

- Ensure more accurate diagnosis through increased access to spirometry.
- Increase education and awareness of COPD risk factors and symptoms for timely diagnosis and prevention.
- Improve access to pulmonary rehabilitation and education programs.
- Empower COPD patients and their families with the use of a written COPD care plan.
- Develop educational programs and clinical tools to ensure high-quality care for people with COPD.

The Conference Board of Canada estimates that by 2030, the number of Canadians with COPD will climb to more than 2.5 million, while direct and indirect costs associated with the disease will reach \$9.45 billion per year. *Helping the Missing Million* is an example of the kind of policy and practice change research that we can pursue through a modernized research program that expands beyond grant-in-aid funding to include behavioural research, clinical trials, digital health solutions, and demonstration projects.



Mind the Gap(s)

What kind of challenges do COPD patients face?

- Family physicians are often a patient's first stop when they develop symptoms, but only 19 per cent feel equipped to handle patients' COPD questions.
- The Canadian Thoracic Society recommends pulmonary rehabilitation as a part of treatment, but only about 15 per cent of patients get to regularly participate.
- Twenty-four per cent of COPD patients say they are not on the best course of treatment because they don't have private drug coverage, or their private drug coverage does not cover the cost of different types of treatment.

Support Spotlight: Programs that Inform & Inspire

“It has made an amazing difference in my husband. He’s not up all night coughing. He’s doing so much better and I think it’s because he’s able to do regular exercise through the Fitness for Breath program.”

Spouse of a Fitness for Breath participant

Fitness for Breath

Chronic lung disease puts many Canadians in a difficult cycle — regular exercise is essential for strengthening their lungs, but lung disease prevents them from pursuing active hobbies and limits them from participating in regular fitness programs.

Now in its sixth year, our Fitness for Breath program is helping meet that need. This innovative respiratory exercise maintenance program helps participants experience the health benefits of aerobic exercise, strength training, and flexibility through classes designed to work with people of any fitness level or ability.

Our fitness partners include YMCAs or other community-based fitness facilities. To date, we have trained more than 90 fitness staff and there are now close to 300 people participating across Ontario. For those communities who do not yet have a Fitness for Breath program, we have developed e-learning modules that provide the necessary background information, education, training and guidelines required to set up a suitable exercise maintenance program for people living with chronic lung conditions.

In 2019/20 we brought Fitness for Breath to two new communities, bringing our total number of locations to 23. With programs now located in every region of Ontario, we look forward to bringing Fitness for Breath to new audiences through expanded locations in 2021 and beyond.

The Lung Health Line

Expert advice is just a phone call, email, or web chat away. The Lung Health Line is a free service that connects users with one-on-one guidance and counselling from a Certified Respiratory Educator.

In 2019/20, our Lung Health Line team answered 2,000+ questions about topics like asthma and COPD management, lung cancer support, medication adherence, smoking/vaping cessation, and more. And thanks to improvements in usability and accessibility, we served more Canadians than ever before through the convenient live chat feature on lunghealth.ca.

Our Lung Health Line is available Monday to Friday, from 8:30 a.m. to 4:30 p.m. EST. If you have questions, we have answers. Reach out to a Certified Respiratory Educator by phone (1-888-344-LUNG), email (info@lunghealth.ca) or live chat at lunghealth.ca.

Certified Respiratory Educators vs. COVID-19

Our Certified Respiratory Educators had a role to play in Canada's earliest attempts to flatten the COVID-19 curve.

By helping people manage their conditions at home and stay out of hospital, services like the Lung Health Line meant that more beds, ventilators and staff were there for the critical COVID-19 patients who needed them. Providing preventative home support also meant that fewer vulnerable patients – like those fighting lung cancer – had to risk going out to visit clinics, pharmacies and emergency departments for the answers they needed.

Support Groups

Each of our 21 lung health support groups are as unique as the volunteers who run them. What unites them is our drive to provide a welcoming and informative environment for patients and caregivers affected by all forms of lung disease.

This year, our support groups served approximately 300 patients and caregivers by providing welcoming meeting places, educational opportunities, access to local speakers, and ongoing phone and resource support. We also launched a call-in support group for those without a support group in their community, or for whom

getting to a group is too difficult. This initiative would prove invaluable once COVID-19 forced groups to cease meeting in person in March 2020.

With a group facilitator e-module in the works, an expanded support group network is on the horizon!

Elevating Patient Voices

Last year was full of opportunities to elevate the voices of the brave Canadians who live the reality of lung disease every single day. From advocating alongside our Lung Health Ambassador team at our Queen's Park Lobby Day in December to helping patients and caregivers contribute to Ontario's drug review process through a whole year of Patient Evidence Submissions, we are privileged to benefit from the wisdom of our patient stakeholder network.

When the COVID-19 crisis hit, our Lung Health Ambassadors even came together (virtually) to make their inspirational video debut, sharing their tips on fostering positive mental health practices in the face of the uncertainty and isolation that came with social distancing.

Education Spotlight: the (mis)Adventures of the Toker

“In a lighthearted way, the Toker highlights the impact that smoking cannabis can have on one’s lungs, as many people aren’t aware that it contains many of the same toxic ingredients as tobacco smoke – like tar, ammonia, and hydrogen cyanide. The goal of this national education effort is to protect the health and safety of young Canadians by giving them the knowledge they need to make informed choices.”

*George Habib,
President & CEO, Lung Health Foundation*

Research shows that few young adults are aware of the lung health risks of cannabis smoke. Last year, we set out to fill this knowledge gap through the Toker, a new comic book-inspired public education campaign aimed at helping 18-to-25-year-old Canadians increase their understanding and make informed choices.

Funded by Health Canada as part of an ongoing initiative to raise awareness about the health effects of cannabis, the Toker campaign followed the (mis)adventures of a superhero slowed down by his cannabis use.

In a series of humorous animated video PSAs, our not-so-superhero illustrated his failure to “save the day” due to respiratory symptoms resulting from his frequent and long-term cannabis use. The character was further brought to life through a series of on-campus activations at universities across Canada and through appearances at educational events like our Better Breathing Conference.

TheTokerOnline.ca (JeanMarieSuperheros.ca) was accessed 122,000+ times during the campaign period. The campaign website gave visitors an evidence-based hub where they could learn to identify the risks associated with inhaled cannabis use, and access links to important peer-reviewed clinical studies. We also introduced visitors to harm reduction tips, with strategies that ranged from healthier product selection to complete cannabis cessation.

The Toker was a hit, netting 1.4 million video views, 28.3 million paid impressions, and 3.6 million earned media impressions. In a follow up survey, 50 per cent of those polled indicated that they would consider changing their behaviour thanks to the campaign.

Earlier last year, a national survey conducted on behalf of the Lung Health Foundation revealed that 64 per cent of 18-to-25-year-old cannabis users wish they knew more about the impact that cannabis smoke could have on their lungs.

Thanks to the ongoing Toker campaign, we are bringing them the information they need to make informed choices about cannabis use.

Unmasking the risks

Smoking is the most harmful method of consuming cannabis, with both short- and long-term effects on lung health. A person's risk of experiencing these symptoms increases over time and with more frequent use.

Get to know the potential downsides, and watch for these symptoms before they slow you down:

- **Airway injuries and inflammation:** Physical changes to the lungs are the arch nemesis of healthy breathing, meaning you may eventually battle coughing, wheezing, shortness of breath and worsening asthma symptoms. You could even develop symptoms of chronic bronchitis.¹
- **Excess sputum:** Sputum (phlegm) is the sidekick you never asked for. It's a mixture of saliva and thick mucus coughed up from the lower respiratory tract.²
- **Bronchospasms:** Good lungs may find themselves squaring off against bronchospasms – a sudden tightening of the muscles in the walls of your airways that leave you fighting for air.³
- **Infections:** Changes to your lungs' immune cells up your risk of facing off against infectious foes like pneumonia, or even fungal or bacterial pathogens from the cannabis plants. Sharing pipes or bongs increases your risk of tuberculosis, too.⁴

Sources:

1. Tashkin Donald P. Effects of marijuana smoking on the lung. *Annals of the American Thoracic Society*. 2013 Jun;10(3):239-47. doi: 10.1513/AnnalsATS.201212-127FR

2. Hancox RJ, Shin HH, Gray AR, Poulton R, Sears MR. Effects of quitting cannabis on respiratory symptoms. *European Respiratory Journal*. 2015;46(1):80-87. doi:10.1183/09031936.00228914

3. Gates P, Jaffe A, Copeland J. Cannabis smoking and respiratory health: Consideration of the literature. *Respirology*. 2014;19(5):655-662. doi:10.1111/resp.12298.

4. Gates P, Jaffe A, Copeland J. Cannabis smoking and respiratory health: Consideration of the literature. *Respirology*. 2014;19(5):655-662. doi:10.1111/resp.12298

Policy Change Spotlight: Immunization Innovation

A universal flu vaccine doesn't exist (yet). It is likely many years away. The development of a single vaccine that provides safe, long-term immunity against the full spectrum of flu viruses is a noble goal, but we recognize that progress will be slow without significant changes to the way Canada prioritizes vaccine research and innovation.

We can't simply wait for a perfect universal flu vaccine. Canadians need protection now, especially those who live with lung diseases like asthma, COPD, and lung cancer. Even without perfect flu protection, the annual vaccine remains our best shot at preventing the flu and its potentially deadly complications. Still, vaccination rates aren't increasing significantly, and one of the top reasons given during public polling is doubt that the current vaccines offer effective protection.

If Canada is to meet its flu vaccination coverage goal for high risk individuals (80 per cent) and exceed the World Health Organization's coverage goal (75 per cent), innovative approaches to the promotion and delivery of influenza vaccines are just as necessary as innovative approaches to the vaccines themselves.

What if we could solve both problems with some outside-the-box thinking?

During our Immunization Innovation Policy Forum roundtable, our expert panel explored the gaps that could be filled in three critical areas: evaluation, delivery, and awareness. Coming out of this innovative session, our policy recommendations include:

- Solving provincial funding and procurement challenges by centralizing funding decisions at the federal level.
- Encouraging innovation through publicly-funded pilot projects that gather real-world data on the safety and effectiveness of new vaccines.
- Improving overall vaccine uptake by standardizing pharmacists' ability to provide vaccinations across Canada.
- Encouraging health-care providers to educate patients about flu vaccination through an incentive-based model.
- Developing province-wide vaccination registries that record which vaccination individuals have received, facilitating the process of evaluating effectiveness among different population groups and seasons.
- Building public awareness of the safety and effectiveness of the influenza vaccine.

Until policies evolve, Canada's patchwork of vaccine approval and funding approaches may delay new vaccine adoption by months or even years. The result: Americans and Australians benefit from vaccines that Canadians can't access.

As we prepare for another annual flu season with the added complication of currently vaccine-less COVID-19, the Lung Health Foundation continues to advocate for policies that move the needle on the issue of novel vaccines.

About our Breathing Policy Forum Series

Our Breathing Policy Forums bring together public and private sector thought leaders to tackle some of the most urgent and pressing issues facing health-care today. From intimate roundtable sessions to large symposia, these collaborative events help the Lung Health Foundation identify creative and actionable solutions and allow us to play a deeper role in shaping public policy.

The People Who Make it Possible

The Lung Health Foundation is building a movement of like-minded individuals and organizations with a shared vision of increasing the urgency of lung disease and empowering Canadians to live healthier lives.

Thank you to the donors and funding partners who made great things possible in 2019/20.

Our donors

More than 32,000 Canadians supported the work of the Lung Health Foundation last year:

64

Canadians made an impact through gifts of \$5000 or more

116

Canadians made an impact through gifts of \$1000 to \$4,999

335

Canadians made an impact through gifts of \$500 to \$999

5,919

Canadians made an impact through gifts of \$100 to \$499

26,286

Canadians made an impact through gifts of \$100

We are grateful for our donors and the commitment they have shown to improving the lives of the 1-in-5 Canadians who live with lung disease.

Our funding partners

The Lung Health Foundation collaborates with others to help accelerate progress in research, provide information to the public, and influence health policy. Thank you to the organizations who helped us achieve our mission this year.

\$200,000 +

Health Canada – Substance Use and Addictions Program
Government of Ontario

\$100,000 - \$199,999

AstraZeneca Canada Inc. | Boehringer Ingelheim Ltd. | Pfizer Canada Inc.
Seqirus Canada | GlaxoSmithKline Inc. | Takeda Canada Inc. | Tetra Bio-Pharma

\$50,000 - \$74,999

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Bristol-Myers Squibb Canada | Merck Canada Inc.

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ProResp Inc. | Novartis Pharma Canada Inc.

\$10,000 - \$24,999

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Sanofi Genzymes | Teva Canada Innovation

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