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Patient Advocacy Day

2020 Policy Package

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About the Lung Health Foundation

The Lung Health Foundation is Canada's primary not-for-profit organization dedicated to the diagnosis, patient care and prevention of lung disease in Canada. As a national organization focused on the lung health of Canadians, we invest in the future by driving groundbreaking research while giving patients and their families the programs and support they need today. Previously known as the Ontario Lung Association, we have expanded our mandate and activities so that we can work with Canadians across the country to fund and find better ways to let us all breathe easy.

Our Commitment:

- Ensuring no one loses a loved one to asthma
- Keeping people with COPD out of hospital and living a full life
- Giving people with lung cancer a fighting chance
- Reducing smoking and vaping to protect the lungs of future generations
- Protecting all Canadians against the impact of COVID-19, and ensuring older adults keep their independence through immunization

Our Vision A world where everyone can breathe easier

Our Mission Improving the lung health of Canadians

Our Partners

Our Lung Health Advisory: a network of the leading lung disease specialists across the country including respirologists, immunologists and thoracic oncologists.

Our Researchers: including physicians, basic and clinical scientists, and other respiratory medical professionals who are uniquely positioned to investigate all aspects of lung disease.

Our Societies: The Ontario Thoracic Society, and the Ontario Respiratory Care Society are our two professional societies made up of respirologists and other multidisciplinary professionals from a variety of disciplines who are involved with respiratory care.

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Asthma

Asthma is a chronic lung disease that can make it difficult to breathe. Asthma causes airways to become tight or swollen and filled with mucus, making it hard for air to pass through. Living with this incurable disease is the reality for over 3.8 million Canadians, including 850,000 children, and the prevalence continues to rise.



Asthma Key Facts



- The proportion of Canadians living with asthma increased by 67% between 2000/01 and 2011/12.¹
- Asthma disproportionately affects children and young Canadians.
- Asthma is more common in Ontario than anywhere else in Canada, with a provincial prevalence rate of 12.08% compared to the national rate of 10.78%.
- From 2017 to 2018, asthma attacks resulted in 64,683 emergency room visits across Canada.²
- According to the Conference Board of Canada, in 2010 the cost of hospitalization for asthma was \$250.7 million. The cost of physicians who cared for asthma patients was \$196.3 million and the cost of medications was \$535.7 million.³

1 Government of Canada. Report from the Canadian Chronic Disease Surveillance System: Asthma and COPD in Canada, 2018.

2 Canadian Institute for Health Information. (2018). Emergency Department Visits: Volumes and Median Length of Stay by Triage Level, Visit Disposition and Main Problem <https://www.cihi.ca/en/nacrs-emergency-department-ed-visits-volumes-and-median-length-of-stay-by-triage-level-visit>

3 Hermus, Greg, Stonebridge, Carole, Goldfarb, Danielle, Thériault, Louis and Bounajm, Fares. (2012). Conference Board of Canada, Cost Risk Analysis for Chronic Lung Disease in Canada <https://www.conferenceboard.ca/e-library/abstract.aspx?did=4585>





Asthma Patient Testimonial

Louisa D,
severe asthma patient



Living with asthma, I make sure to take precautions and use my prescribed inhalers. However, in 2019, I experienced two pneumonia infections which resulted in severe asthma attacks. Both times the pneumonia caused me to visit the hospital emergency department. One attack required an ICU visit and a 10-day stay and another, an emergency visit for possible pulmonary embolism then I was sent home from the hospital without treatment. Later only to be left going to an urgent clinic to be treated for pneumonia. The outcome of these visits taught me how important it is to be prepared for coordinating my own lung healthcare path e.g. ongoing doctor visits - referral to doctors/specialists, asking the right questions, and to be accompanied and not alone when going to the emergency department.

I am sincerely thankful to the Lung Health Foundation for allowing me to participate in the Lung Health Foundation support group. The group is a respectful and informative

place for me to lean on during these times after my prognosis of severe asthma. I am on a treatment plan and through multiple CT scans I am now being monitored for lung cancer and heart disease.

Sharing and learning from participants who are living with other forms of lung disease is an uplifting relief. The group facilitators and speakers bring professionalism, compassion, knowledge and understanding to the group. The Lung Health Foundation support group facilitators secure a forum of speakers made available to our community that come together. We share lessons-learned; bring questions that are answered with follow-up before and after meetings by the facilitator, through prompt telephone and email communications. Personally, it helps to alleviate stressors, fear and anxiety. As participants we all benefit and these meetings may help to off-load the amount of work on doctors, specialists, and front line workers as they help patients maneuver the healthcare system.



Our Asthma Recommendations

1. Sustain funding for the Lung Health Foundation's Asthma Action Program

The Asthma Action Program gives adults and children with asthma, their caregivers, healthcare providers, and the general public access to information and support to improve control of asthma and lead to reduced asthma morbidity, mortality and healthcare costs in Ontario. We work to fill the gaps that exist for patients in terms of diagnosis, treatment, education and management, through educational resources and events, live counselling from certified respiratory educators, and supportive services, for patients and healthcare providers. This vital work is strengthened through the engagement of panels of experts that sit on various provincial committees, including an overarching Asthma Advisory Committee. The committee assists in monitoring program outcomes and guiding future directions. Recently, the Asthma Action Program has also been expanded to provide supports to Ontarians living with chronic obstructive pulmonary disease (COPD).

The funding we receive from the Government of Ontario supports the sustainability and evolution of programs such as: the Lung Health Line, a toll free line accessible to all Ontarians via telephone, email, and online chat function; awareness campaigns, resources, and publications dedicated to educating people affected by asthma and COPD; and the Primary Care Asthma Program which offers patients a standardized and effective approach to care with their family doctor. These programs have proven to be very effective and have had positive outcomes in reducing emergency room visits, and improving health outcomes for patients. With rising prevalence rates, and the burden asthma continues to place on the healthcare system, continued support for the management of asthma is desperately needed. With this, we call on the Government of Ontario to ensure sustained funding to the Asthma Action Program.





2. Promote Ontario Health's Asthma Quality Standards

We commend the Government of Ontario on its release of quality standards for adults with asthma earlier this year. These standards are critically important to improving quality care in asthma and ensuring optimal management for patients. We see that in practice, not all of the standards and processes outlined in the document are being implemented at the clinician level. Specifically for adult patients with severe asthma, there continues to be challenges and knowledge gaps among healthcare providers in diagnosing and treating severe asthma.

The Lung Health Foundation is dedicated to doing our part to empower patients to be their own self-advocates by developing patient facing documents and raising awareness of the quality of care that patients should expect to have. We support the need for Ontario Health to promote the necessity of implementing these standards to Ontario Health Teams and healthcare providers across the province. Doing so will improve early detection of the disease, ensure patients are on the right treatment regimen, and ultimately reduce hospitalizations and save healthcare dollars.



Chronic Obstructive Pulmonary Disease

Chronic obstructive pulmonary disease (COPD) is the name for a group of lung diseases that causes lung damage and blocks the airways. It includes chronic bronchitis and emphysema.





COPD

Key Facts

- There are an estimated 900,000 Ontarians living with COPD. It is the leading cause of hospitalization (after child birth) and it represents the highest number of readmissions.⁴
- About 1-in-5 patients with COPD are readmitted to acute inpatient care within 30 days.⁵
- Not only are a majority of patients unaware of what COPD is, of those who experience symptoms, less than half receive a spirometry test to properly diagnose them.
- High risk individuals are current and former smokers over the age of 40 who are experiencing any of COPD symptoms such as shortness of breath or heavy phlegm.

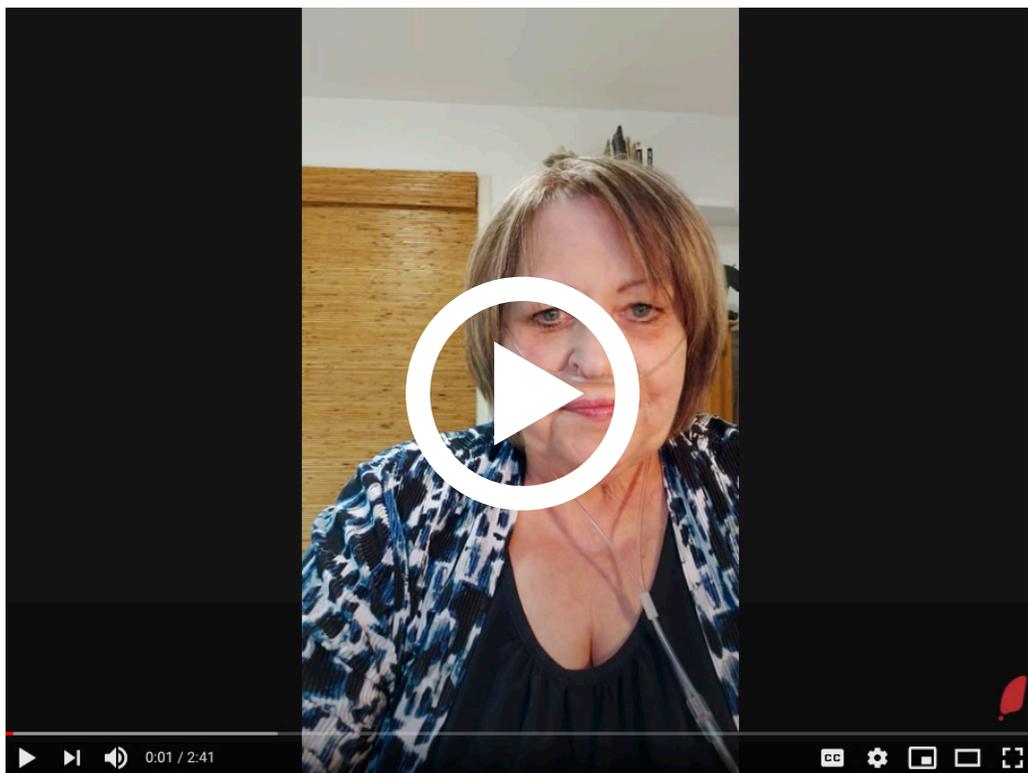
4 Canadian Institute for Health Information (2020). Inpatient Hospitalization, Surgery and Newborn Statistics 2018-2019.

5 Gershon AS, Thiruchelvam D, Aaron S, et al. Socioeconomic status (SES) and 30-day hospital readmissions for chronic obstructive pulmonary (COPD) disease: A population-based cohort study. PLoS One. 2019;14(5):e0216741. Published 2019 May 21. doi:10.1371/journal.pone.0216741



Patient Testimonial

Barbara Moore,
COPD Patient Advocate





Our COPD Recommendations

3. **Develop a targeted screening program in Ontario to test those who are at high risk of COPD.**

Currently, COPD patients are being underdiagnosed and not receiving the care that they require, and over diagnosed and being put on the wrong treatment regimen- both of which can lead to exacerbations and unnecessary hospitalization. We believe that one part of the solution is to get COPD patients diagnosed faster using spirometry testing. To do this we suggest developing a targeted screening program to test those who are at high-risk of COPD using a spirometry test (standard breathing test).

A COPD screening program would function similarly to Cancer Care Ontario's cancer screening program. However, instead of only a letter with a call to action to receive a diagnostic test, the letter would also include a questionnaire of symptoms and risk factors so individuals know whether or not they should seek a spirometry test.

We're certain that implementing a program like this will lead to improved outcomes on various fronts. This includes improving general awareness of the disease and its risk factors, improving patient outcomes by diagnosing them quicker and getting them on the right treatment, and ultimately leading to reduced rates of hospitalization and savings on healthcare spending.



We believe that one part of the solution is to get COPD patients diagnosed faster using spirometry testing.



4. Partner with the Lung Health Foundation to provide COPD remote monitoring care to individuals eligible for long-term care.

In Budget 2020 the Ontario government announced a new community paramedicine program as a means to support seniors on long-term care waitlists. The pilot program will provide individuals eligible for long-term care with 24/7 access to non-emergency support, through home visits and remote monitoring. We believe this program can be expanded to include tailored support for COPD patients.

COPD patients are generally outpatients, with the exception of when they suffer an exacerbation and require hospitalization. In many jurisdictions, remote monitoring has been found to both reduce the frequency and severity of exacerbations. Through remote monitoring tools such as calls, videoconference, and email, exacerbations can be predicted before they occur, at home treatment during mild exacerbations can be monitored, and self-management practices such as daily exercise can also be monitored.

The Lung Health Foundations certified respiratory educators already provide information and guidance to COPD patients through our Lung Health Line and are equipped with the knowledge and expertise necessary for remote monitoring.



Lung Cancer

Lung cancer is the leading cause of cancer death in Canada. More people are expected to die from the disease than from colorectal, breast and pancreatic cancer combined.⁶

6 Canadian Cancer Statistics Advisory Committee. (2019). Canadian Cancer Statistics 2019 cancer.ca/Canadian-Cancer-Statistics-2019-EN



Lung Cancer Key Facts



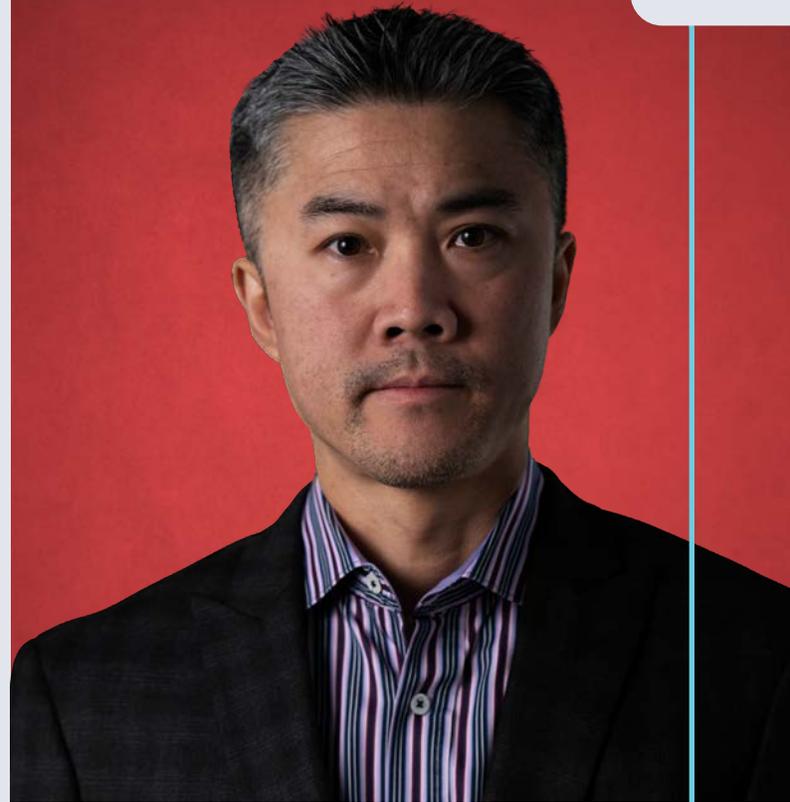
- It is estimated that 29,800 Canadians will be diagnosed with lung cancer in 2020. This represents 13% of all new cancer cases.
- 21,200 Canadians will die from lung cancer in 2020.
- 58 families lose a loved one to lung cancer every day in Canada. It is responsible for 1-in-4 cancer deaths.
- In Canada, the five-year net survival rate for lung cancer is 19%. This means that about 19% of people diagnosed with lung cancer will survive for at least five years after their diagnosis.





Patient Testimonial

**Alan Soon,
Lung Cancer Patient**





Our Lung Cancer Recommendations

5. Adopt a comprehensive lung cancer screening program in Ontario

For patients with lung cancer, early detection is everything. If a high-risk individual is diagnosed before the onset of symptoms, when the cancer is in an early stage, the chances of survival are very good. In Canada, almost 50 per cent of lung cancer is diagnosed at stage IV, an incurable stage. With the proper screening protocols in place, 75 per cent of diagnoses are at an early stage, when curative treatment is possible.

In 2016, the Canadian Task Force for Preventative Health recommended lung cancer screening using low dose CT (LDCT) “for high risk adults ages 55-74”. While this has led to various provincial pilot projects that screen high-risk individuals, British Columbia is the only Canadian jurisdiction that recently announced their plans to implement a screening program by the spring of 2022. There is a need to expand Ontario’s pilot program, as is being done in B.C., to ensure individuals across the province have access to early screening.





6. Develop an oral cancer drug program

Oral cancer medication is publicly covered by all of the western provinces, Quebec, and the territories. Ontario and the Atlantic provinces are lagging behind in their coverage of important cancer medications.⁷ In Ontario, oral cancer drugs are only covered under the Ontario Drug Benefit (ODB) and the Trillium Drug Program for those age 65+, receiving social assistance, or with limited private insurance. In contrast, IV cancer drugs are publicly covered for all Ontarians because they are administered in-hospital.

Oftentimes, patients are forced to seek crowdfunding for treatment or they're left to make tough choices. Many new cancer treatment drugs are approved but not yet funded, resulting in delayed, or no access. Ontario should follow in the footsteps of other provinces and develop an approach to provide easy access to cancer drugs. For example, in Manitoba, the government has implemented a home cancer drug program that allows all Manitobans to access certain publicly funded oral cancer medications.⁸

*For more information on the social, economic and mental health issues of Canadians living with lung cancer and recommended solutions to these challenges, please download the **Lung Health Foundation's and Lung Cancer Canada's policy report.***

7 http://www.cameroninstitute.org/wp-content/uploads/2014/10/084_10.5923.jajmms_20140404.05.pdf
8 <https://www.cancercares.mb.ca/Treatments/pharmacy/home-cancer-drug-program>

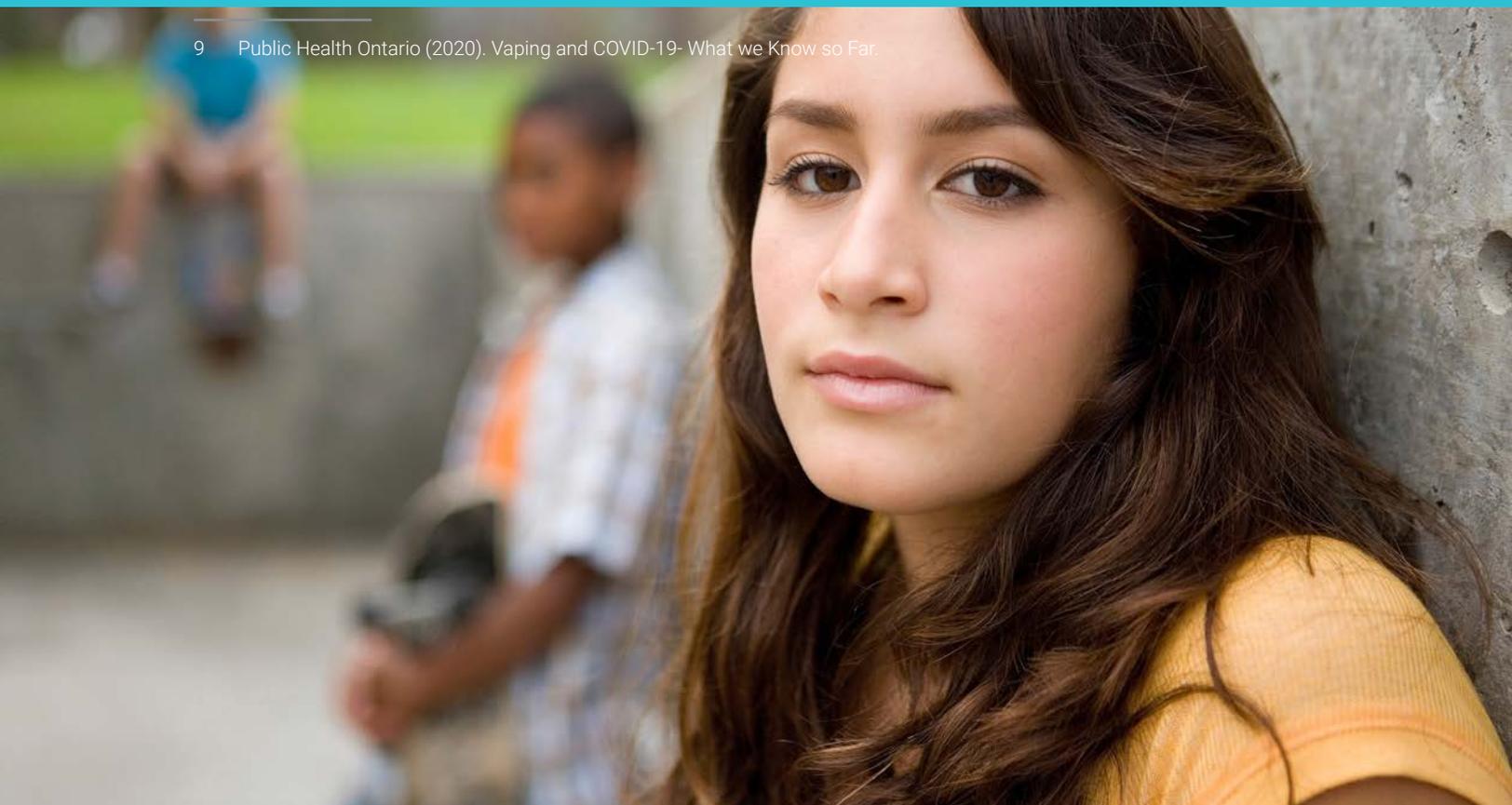


Youth Vaping Cessation

E-cigarettes/vapes are battery operated devices (typically containing nicotine) that, when heated, produce an aerosol that contains many toxic chemicals.⁹

Canada is undeniably facing a youth vaping epidemic with youth vaping rates increasing by 74% from 2017 to 2018. While the long-term health effects of vaping remains unknown, the short term health impacts being seen and the correlation to subsequent cigarette use among youth, is troubling and makes a case for immediate government action.

9 Public Health Ontario (2020). Vaping and COVID-19- What we Know so Far.



Youth Vaping Key Facts



- A recent Stanford study found that youth vaping use makes them five times more likely to contract COVID-19.¹⁰
- In Ontario, 23% of teens reported using an e-cigarette in 2019 according to a CAMH study.¹¹
- In Canada there have been 20 cases of vaping associated lung injury (EVALI) since May 2019. The exact causes of these serious injuries remains unknown.
- Preliminary evidence shows that vaping products act as a gateway to smoking cigarettes. An Environics Research survey found that about 32% of youth (aged 15-19) dual user's vaped before smoking.¹²

10 Gaiha, S. M., Cheng, J., & Halpern-Felsher, B. (2020). Association between youth smoking, electronic cigarette use, and COVID-19. *Journal of adolescent health*, 67(4), 519-523.

11 CAMH (2020). Ontario Student Drug Use and Mental Health Survey.

12 Jubas-Malz D. E-Cigarette and Combustible Tobacco Use: Attitudes and Behaviours. A Synthesis of Findings from Health Canada Public Opinion Research. Special Report. Toronto ON: Ontario Tobacco Research Unit; March 2020.





Youth Vaping Advocate Testimonial

Aiden, Lung Health Foundation Youth Vaping Advisory Council Member



I thought I was going to be different. Only using the vape juice without nicotine would be a fine excuse to let me start vaping with my friends. The tricks are cool, and we wanted to learn them all. This was all happening before the Nords and the \$10 “Nic sticks” were around, so I was oblivious to how bad the addiction was going to get. As my friend and I continued vaping, he got an RDA, or a coil you have to build yourself and that blew bigger clouds. I even figured out that the higher VG in the vape juice, the bigger and more full the clouds would be. I thought I knew it all.

The same year, I joined a personal fitness class, and all the other guys were vaping with nicotine in their vapes, mind you it was weak. As some people with a weaker will sometimes do, I succumbed to the pressure of my peers and started vaping with nicotine. This was around the time vapes were getting smaller, more powerful and the juice was becoming more concentrated. I got caught with my other vape I used for tricks so I was already mad about that, and I figured since I knew so much about

the product, and that it was “new tech”, that I knew better than my parents. This led me to buying my own Juul. Juul was different from the other vapes because the company figured out a temperature where they could highly concentrate the nicotine and the users would barely realize what was happening to their lungs.

The nicotine addiction went between vaping and smoking cigarettes, with my own self not understanding the decisions I was making, how it was affecting my health, my relationships and my self-image. Every time I hit the vape I was lying to myself, saying it would’ve been my last time. I said to everyone that “I know I could stop vaping whenever I want, but there isn’t too much harm in it.” Which obviously didn’t work the way I wished. It took me years to realize the effect nicotine was having on me, and I’m thankful I’m done lying to myself. Nicotine is one of the most profitable substances on the planet, and although it is widely accepted, it shouldn’t be normalized, especially among the younger generations.



Our Youth Vaping Recommendations

7. Implement a provincial sales tax on vapes and vape products.

Implementing a tax on vaping products would serve as a disincentive to youth to initiate using vape products given the price sensitivity of this age group. Other Canadian jurisdictions, including B.C. and Alberta have set a 20 per cent tax on vaping products. In B.C., the government introduced a stand-alone bill to implement an ad valorem tax on both vape devices and liquids. The province decided not subject cannabis products (except for liquid cannabis products) to the tax due to agreements with the federal government.

Vaping products are currently much more affordable than cigarettes in Ontario. The point is not to make e-cigarettes more expensive than cigarettes but it's to discourage youth from starting on vapes. The effectiveness of vapes as a smoking cessation tool is not established and evidence remains inconclusive. According to OTRU data, only 15 per cent of e-cigarette users were former smokers, about two thirds are dual users of cigarettes and e-cigarettes suggesting that the majority of e-cigarette users are not using the products for smoking cessation reasons, or have been unsuccessful in their efforts. While much more high-quality research is necessary, this does not take away from the need to adopt a vaping tax to curb youth vaping rates.





8. Introduce tighter regulations around vaping products including: banning flavored products (except by prescription), and adopting a comprehensive ban on e-cigarette marketing.

A Canadian survey conducted by the Heart & Stroke Foundation found that 92 per cent of teens reported flavor was a main reason why they began to vape.¹³ Canada's Tobacco and Vaping Products Act bans the advertisement of flavors that could appeal to youth, but places no restrictions on the actual flavors. Ontario has introduced restrictions on the sale of flavored vape products to specialty vape and cannabis retail stores (with the exception of menthol, mint, and tobacco flavors which can be sold in non-retail stores), yet youth in Ontario are still able to easily access flavors. The research suggests that adult only vape stores continue to sell products to minors, and youth can easily access flavored products online or through older friends or family. Allowing flavors only in medicinal products would restrict youth access and allow for greater oversight.¹⁴

In relation to vaping advertising, the current approach in Canada is to restrict advertising so it is not youth appealing. However, it is evident from public opinion studies that youth are being exposed to large amounts of marketing from a variety of sources. Restrictions implemented should be similar to the ones placed on tobacco products which would apply to all venues and include conditions requiring plain packaging. Outlining an exception whereby doctors or pharmacists can promote the use of e-cigarettes to patients would allow for awareness of vapes as potential smoking cessation device to be raised.¹⁵

13 Heart and Stroke Foundation of Canada (2020) The 2020 Youth and Young Adult Vaping Project.

14 Ontario Tobacco Research Unit (2020). E- Cigarette Flavors: Theory, Evidence and Regulatory Policy.

15 Ontario Tobacco Research Unit (2020). E- Cigarette Marketing: Theory, Evidence and Regulatory Policy.



Infectious Respiratory Disease

Preventing infectious respiratory diseases is integral to our work given the human and economic toll that diseases like flu, pneumonia, and now COVID-19 place on the healthcare system. The issues being faced in the 2020 flu season shed light on the need for greater public education and facilitating access to vaccines.



Infectious Respiratory Disease Key Facts



- In 2017-18, pneumonia led to 138,485 emergency department visits across Canada. It was the ninth leading cause of a trip to the ER.
- Influenza contributes to an average of 12,200 hospitalizations and average of 3,500 deaths across Canada annually.
- In the 2018-19 season, the most common reason reported by those 65+ for not receiving a pneumococcal vaccine was the view that the vaccine is not necessary.¹⁶
- In the 2019-19 season, 41 percent of respondents reported that they believe the flu vaccine does not protect against the flu and 43 percent believed they might get the flu from the vaccine.¹⁷

¹⁶ Public Health Agency of Canada (2019). Vaccine Uptake in Canadian Adults 2019.

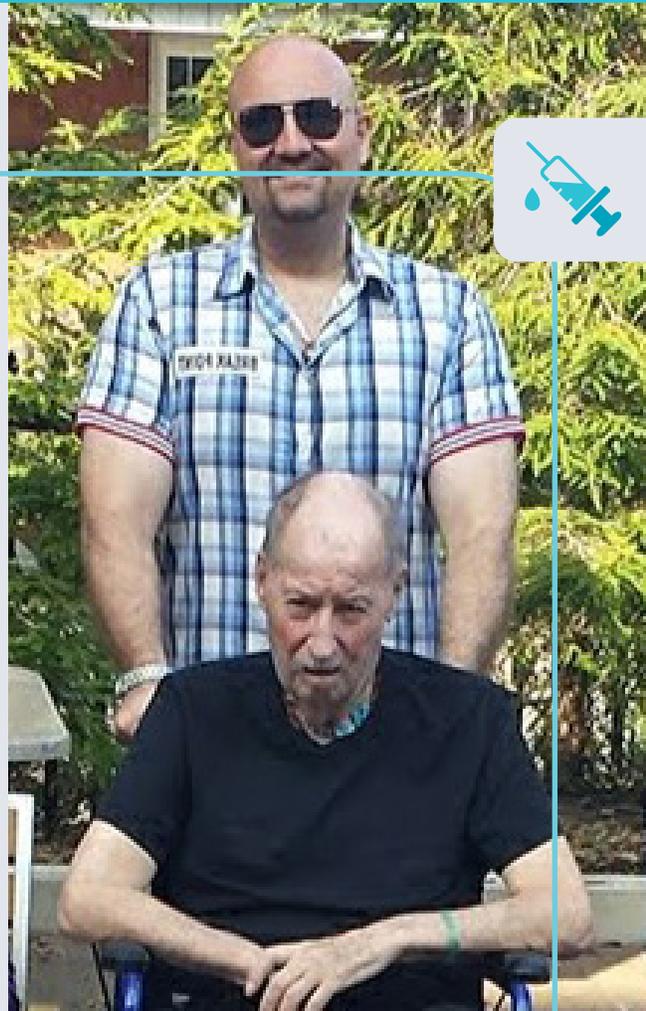
¹⁷ Ibid.





Infectious Respiratory Disease Advocate Testimonial

Umberto Leone,
Caregiver Advocate





Our Infectious Respiratory Disease Recommendations

9. Partner with the Lung Health Foundation on a public education campaign to augment the messaging on the importance of immunizing before the release of a COVID-19 vaccine.

Canadians are bombarded with misinformation about the flu vaccination and COVID-19 daily through social media. Currently, sentiments of vaccine hesitancy are widespread among the public and could lead to significant challenges for all areas of infectious disease if not addressed. Further, Canadians have little faith in institutions. They trust respected health organizations for information over government calls to action. In preparation for the COVID-19 vaccine and next year's flu season we believe in the need for province-wide messaging that is consistent and factual in order to foster public trust in the safety and efficacy of vaccines.

The Lung Health Foundation's public education campaigns exceed industry benchmarks. We are proven effective in inspiring behavior change and are doing it already with our immunization campaign that is in-market now. Addressing vaccine hesitancy head-on will require a collective voice and we are certain we can amplify the Government of Ontario's messaging.





10. Ensure that vaccines that offer greater protection against influenza and pneumococcal pneumonia are easily accessible in Ontario by utilizing various settings, ordering sufficient supply, and publicly funding important vaccines.

The Public Health Agency of Canada recommended this year that in order to reduce crowding at clinics and increase accessibility and uptake, non-traditional settings including grocery stores, parking lots, drive-through clinics, homecare visits, student residences etc. should be utilized. These type of settings should continue to be utilized, even in a post-pandemic world. While this year was the first year that the high dose flu vaccine was available to seniors and vulnerable populations at pharmacies, not enough supply was ordered to keep up with demand. Further, a strategy was not put in place to ensure at risk populations can receive vaccines at home. Moving forward, the province should pursue measures that guarantee safe access to the vaccines that offer the best protection for vulnerable populations.

In addition, while allowing pharmacists to administer vaccines has led to increased uptake, many vaccines are not available for pharmacies to order. Vaccines that are not publicly funded are not available for pharmacists to order even if individuals would like to pay out-of-pocket to receive these vaccines that could offer greater protection. Giving pharmacists more flexibility on which vaccines they can order and administer would facilitate vaccine accessibility to different population groups.

Lastly, financial burden is a significant barrier to adult immunization in Ontario. For example, while Ontario publicly funds the pneumococcal polysaccharide vaccine for adults 65 years of age and older, it does not fund the pneumococcal conjugate for this age group- which has been proven to provide additional protection against pneumococcal disease.



For more information
on our work or our policy recommendations
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