

# THE CAMPAIGN FOR LUNG RESEARCH



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 THE LUNG  
ASSOCIATION™  
Ontario



# BREATHING AS ONE

**W**e're all in this together – each of us inhaling and exhaling about 20,000 times a day, every day of our lives. And just as our lungs work together to oxygenate our blood, Ontarians need to work together to tackle the challenges of breathing.

We need to radically change the way we think about breathing – what we do to enable it, the therapies we use to treat it and what we can do to safeguard it. That's the idea behind Breathing as One: The Campaign for Lung Research, The Lung Association's ambitious campaign to rally Canadians under the banner of better breathing.

The statistics on lung disease in our province, already daunting, are moving in the wrong direction. More than 2.4 million Ontarians currently have lung disease; chronic obstructive pulmonary disease has become the number one cause of hospitalization in Ontario; one in five children in our schools has asthma; and lung cancer is killing more people than breast, ovarian and prostate cancer combined.

Despite these sobering facts, lung disease receives a tiny proportion of research funding compared with the other chronic diseases. The impact of this is devastating. Lack of funds means less research and less chance of new discoveries in the prevention, diagnosis and treatment of lung disease.

Working together – and Breathing as One – we can change that trajectory and, in the process, create the kind of world where everything is designed to protect our precious breath.

This ambitious campaign is organized under three pillars:

**1. MONEY** We need to be able to support exceptional researchers with ongoing funding that takes them into new, uncharted areas of integrated, multi-disciplinary investigation.

**2. MENTORSHIP** Not only must we build capacity by attracting promising young minds into respiratory research, we also have a responsibility to partner the next generation of scientists with the most knowledgeable and inspiring advisors.

**3. MEANING** We need to take all of this learning into the real world by converting research into concrete guidelines, practices and treatments, designs and policy.

November is Lung Month in Canada, a time when the Ontario Lung Association reaches out to all residents of the province with information on how to protect and care for their lungs – and how to recognize problems in the early stages – so they can save their breath. With the launch of the Breathing as One Campaign, we introduce a new way of thinking about breathing and a new approach to dealing with lung disease.

On the following pages, you'll meet some of the people who are working tirelessly to improve lung health and also some of the people who will benefit from our campaign to make lung research a priority.

## On the cover



**Dr. Chung Wai-Chow** is a member of Toronto General Hospital's world-renowned lung transplant team. She also conducts groundbreaking research into treatments that could counter the harmful effects of air pollution. Her current research measures traffic-related pollutants and their uptake into the body.



**Dr. Dawn Bowdish's** research at McMaster University focuses on the causes of pneumonia infections among the elderly. She's doing her part to ensure the health and well-being of our parents and grandparents. **Story pg. 3**



**Dr. John Granton** is one of Canada's leading respirologists. As Head of Respiriology and consultant in critical care and lung transplantation at Toronto's University Health Network, he is furthering our knowledge of lung injury, thrombosis and pulmonary vascular disease. As honorary chair of The Lung Association's national Breathing as One campaign for lung research he is helping to ensure that a new generation of researchers can continue that vital work.



**Gabriel Roosevelt-Jackman's** asthma is so severe he needs to visit the hospital every two weeks for tests and injections. He hopes for the day when a game of pick-up basketball or band practice won't pose a potential threat to his health. **Story pg. 4**



**Susan Tremblett's** daughter, Kayla Baker, was a brave lung health champion who died on New Year's Day at the age of 15. Susan carries on Kayla's mission to raise awareness about the need for lung research funding by organizing Cambridge's annual RunaLung event, which now supports a research award named in Kayla's honour.



**Joseph Neale** is a young lung cancer survivor, a singer, and a full-throated advocate for lung research. He's living proof that lung cancer can no longer be dubbed 'the smoker's disease.' **Story pg. 3**

*If you'd like more information about getting involved in the Breathing as One Campaign, go to [www.breathingasone.ca](http://www.breathingasone.ca)*

## A LUNG CANCER SURVIVOR RAISES HIS VOICE



**J**oseph Neale's voice is clear and soulful. It's hard to believe that two years ago he had two-thirds of his right lung removed after being diagnosed with lung cancer.

The talented singer-songwriter was just 20 years old when he was referred to Dr. Carmine Simone, a thoracic surgeon at Toronto East General Hospital. He had been complaining of a dry mouth and cough. Though an initial chest X-ray suggested pneumonia, a subsequent CT scan indicated he had a tumour.

"I was terrified," says Neale. His thoughts quickly turned to his baby daughter and his dreams of a music career. Neale, who has never smoked, lost his cousin, well-known musician Haydain Neale of the band Jack-soul, to lung cancer in 2009.

The tumour was considered moderate to large but

had not spread outside his lungs. Surgery was the best option for an otherwise healthy, young patient, but Neale had legitimate concerns about how it would affect his voice.

"I wanted to sing, so surgery for me was out of the question at first," says Neale. "I was going through it in my mind, 'I don't know how I'm going to be singing. I don't know how things are going to change.'"

Fortunately, the surgery was successful. Neale says he actually began to sing in the recovery room until his brothers Jared and David, concerned for his recovery, yelled at him to stop. Two years later and Neale is still displaying that indomitable spirit when he talks about living with only part of his lung.

*"I wanted to sing, so surgery for me was out of the question at first."*

"Sometimes I feel the difference and the emptiness on one side, and it's different to cope with, but I've been doing everything regularly, playing basketball, running, working out and singing, holding my notes," he says.

Now Neale is using his musical talent to advocate for lung cancer awareness and desperately needed research funding.

Lung cancer is the number one cancer killer in men and women. There are more deaths from lung cancer than from the next three most common cancers combined and yet lung cancer receives only a very small portion of cancer-related research dollars.

Dr. Simone thinks breast and prostate cancer are well supported because there are now so many survivors who use their voices to raise awareness. Lung cancer also carries the stigma attached to smoking, although 15 per cent of lung cancers have nothing to

do with smoking.

"We don't have a lot of voices for lung cancer, because, unfortunately, most lung

cancer patients pass away," says Dr. Simone. "Having someone like Joseph stand up and do this is huge. We need voices like his to really get the message out there."

## A PRECIOUS GIFT FOR THE GRANDCHILDREN

**D**r. Dawn Bowdish doesn't need to go far to find inspiration for her research into the Streptococcus pneumonia bacteria, a major cause of pneumonia and a leading cause of death and hospitalization in older adults. She just has to stand by and watch the fun and love that fills the room when her children get a visit from their grandparents.

Dr. Bowdish's overarching research goal is to help older adults live more years of healthy independence. As a mother of two young children, she says she is motivated by the idea that she could help give her children more quality time with their



grandparents. "You can't have a healthy old age without good lungs," says Dr. Bowdish, who is an assistant professor in pathology and molecular medicine at McMaster University.

Pneumonia is particularly difficult to treat in older patients and is a huge burden on our health-care system. When it doesn't kill, its effects often put older patients on a slippery slope towards poorer and poorer health, leading to other diseases such as type-2 diabetes and dementia.

Her research takes a "bench-to-bed-side approach." Her lab houses a colony of mice that are about two years old, which corresponds to about 75 to 85 people years. Dr. Bowdish studies the aging mice to try to understand what makes them so much more susceptible to pneumonia than younger mice.

"Specifically, we are trying to find out why their immune cells seem unable to deal with pneumonia when they are still pretty good at dealing with other infections," she says.

Dr. Bowdish is also working to translate her scientific research into clinical trials by testing the use of probiotics and anti-inflammatory supplements in older adults. Probiotics, for example, may be able to replenish good bacterial communities, making older adults less prone to infection.

Unfortunately, lung health research is underfunded in Canada, says Dr. Bowdish. "Because lung health is so integral to healthy aging, this is a huge oversight as our population ages. We really do need to remedy this quickly."

Dr. Bowdish emphasizes the importance of more funding for basic scientific research. "Without basic research, the impact of clinical research tends to be small and superficial rather than game changing," she says. "I do the science that will change lives in 15 to 20 years, and we need to have a continual pipeline of that to keep innovating and bringing things to the clinic."



# QUESTIONS ABOUT YOUR BREATHING?

Call the Lung Health Information Line at **1.888.344.LUNG** to speak to a Certified Respiratory Educator about:  
**ASTHMA | AIR QUALITY | COPD | QUITTING SMOKING | FLU SHOTS | RADON**

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## BROTHERS' ASTHMA MEANS A LIFE OF 'LITTLE SCARES'

**G**abriel Roosevelt-Jackman was a tiny three-week-old baby when he made his first ambulance trip to the hospital emergency department. Parents Daniel and Ann thought it was a bad cold but Gabriel actually had a serious respiratory infection -- and severe allergic asthma.

Now 13 years old, Gabriel's asthma is so difficult to control that it often prevents him from participating in his favourite sports -- basketball, soccer and football -- something that doesn't usually happen to children with less severe asthma. His seven-year-old brother Solomon's asthma is less problematic but even he knows that he'll have to miss out on gym if he doesn't have his emergency inhaler. "Sometimes, I really want to have the chance to grow out of it," says Solomon.

For the Roosevelt-Jackman family, having two children with asthma means visits to the respiratory clinic

at SickKids every two weeks, lots of medication and lots of uncertainty about when the next asthma flare-up might occur.

It also means keeping a close eye on the weather forecast. "If I go outside and it's really hot, it will affect my breathing and then I'll have to go to an emergency room," Gabriel explains. Cold weather has the same effect.

Solomon's case is different. He was fine until the age of two when mould in the family's apartment triggered the onset of asthma symptoms. At recess re-

cently, Solomon started to have difficulty breathing -- and he had forgotten his inhaler. Ann was stuck on the train, feeling helpless. "But he said he drank some water and he breathed in and out and it calmed him down." It's incidents like this that Ann describes as the "little scares."

The boys' biweekly visits to SickKids are for tests that measure how well the lungs are functioning. Gabriel also gets two injections because of the severity of his chronic asthma and other allergies.



The Roosevelt-Jackman family (from left) Lahreena, Daniel, Gabriel, Ann, Solomon and Callista.

Ann says she worries about Gabriel taking so much medication but she realizes that there are no viable alternatives, especially since he also has multiple food allergies including soya, kiwi, seafood and nuts. Daniel and Ann have no respiratory problems and neither do their two daughters, Lahreena, 10, and Callista, 16.

"It's heartbreaking," says Daniel. "We are actively doing everything, the doctors are actively doing everything but...there are so many sources that can cause a flare-up. It's so tough to control."

Still, through the years of treatment and visits to the clinic and the emergency department, the members of the Roosevelt-Jackman family have learned to cope, to support each other and to be happy. "Despite the challenges, we are blessed," says Daniel.

## Helping researchers to pick winners

*Predicting whether potential new asthma drugs will be effective is all in a day's work for Dr. Paul O'Byrne, principal investigator for the AllerGen Clinical Investigator Collaborative (CIC).*

*He leads a nationwide network of researchers who use*

*a specific clinical model of "allergen-induced, airway responses" to try to understand the way asthma develops, including the role of environmental allergens. That model has also proved highly effective in evaluating the effectiveness of new asthma medications.*

*"It's particularly useful to large pharmaceutical companies as well as small biotech companies who are trying to decide whether to invest the huge sums involved in getting a new drug to market," says Dr. O'Byrne, who is also executive director of the Firestone Institute for Respiratory Health at St. Joseph's Healthcare in Hamilton.*

*With six sites across Canada and one in Stockholm, the project is part of the federally-funded Allergen NCE, the Allergy, Genes and Environment Network, established in 2004 in response to the fact that one in three Canadians lives with allergic disease.*

*Dr. O'Byrne says that although Canada is still a leader in asthma research, new funding priorities are creating challenges for the research community. "Ten to 15 years ago, companies were interested in understanding the basic mechanisms of disease and would invest in studies to find out what was going on in the airways of people with asthma," he explains. "Their funding is much more directed these days."*

*Still, he's very optimistic about the future of asthma research and treatment in this country. He recalls, as a young physician, seeing asthma patients on ventilators in the intensive care unit. "That hardly ever happens now. And knowing that we've made a difference as a group of scientists and physicians is very rewarding."*



*"If I go outside and it's really hot, it will affect my breathing."*

## A TALE OF TWO TRANSPLANTS

*Two men who received new lungs – and new lives – thanks to the renowned transplant program at Toronto General Hospital*



**K**eith Childerhouse was 25 when he was diagnosed with a rare form of severe, progressive lung disease. He was, he says, “a regular guy livin’ the life,” who enjoyed biking, run-

ning, rollerblading and back country camping.

He coped with the disease until it finally stopped him in his tracks in 2012. Even with oxygen supplements, Keith could only walk about 50 yards before running out of breath. At 41 years old, he was told that without a double lung transplant, he had a year to live.

What is it like to live without having enough air to breathe? “It’s like being underwater and not being able to get to the surface,” Keith says. “You want to take that breath, but you can’t.”

In January last year, Keith entered Toronto General Hospital (TGH) to wait for his transplant.

“I could only move from the bed to a chair. My lungs were so bad that on January 29, I was scheduled to be put on an artificial lung to keep me breathing.”

Keith will never forget that date. It was also the day that he received the news that a pair of donated lungs was waiting for him.

Thanks to the TGH Lung Transplant Program and his donor, Keith is ‘livin’ the life’ again. He married last October and in summer competed in the annual Canadian Transplant Games in New Brunswick, taking home medals in three of the five events he entered.

“Why not?” he says. “You only live once.”



**I**n March, 2011, Rob Alexander-Carew was a fit, active husband and father of two young daughters who was troubled by a persistent cough. His doctor sent him for an X-

ray and then gave him the frightening diagnosis: idiopathic pulmonary fibrosis (IPF), a disease which causes scarring in the lungs. There is no cure.

Worse, further investigation showed that Rob’s disease was a fast-moving and aggressive type that gave him a life expectancy of just one to five years. “My only option was to wait until I got sick enough for a lung transplant,” he says.

In preparation, Rob dedicated himself to becoming as fit as possible by working out at TGH three times a week. But just a year after his diagnosis, he realized his health was going downhill quickly. “From March until June, 2012, my limits were decreasing almost weekly,” he says.

At 9 a.m. on June 30, 2012, he got the call from TGH that saved his life. When he woke up from double-lung transplant surgery, Rob took his first deep breath in years.

Now Rob is back at work and recently celebrated his 15th wedding anniversary. In his spare time, he is involved in campaigns to support organ and tissue donation and lung research.

“Until my transplant, I’d needed two people to help me just get up the stairs,” he says. “My life has changed so much. Now I can do the ordinary things again.”

## A DRUG-FREE TREATMENT FOR BLOCKED AIRWAYS

More than 850,000 Ontarians live with chronic obstructive pulmonary disease (COPD). For many that means living with a persistent cough and shortness of breath caused by airways that are partially blocked with mucus. Excess mucus production also affects patients with other lung diseases such as cystic fibrosis and bronchiectasis. As Catherine M. learned, it can make even simple activities difficult.

“Most take breathing for granted, but for those with lung disease it can be very hard work,” she says. The constant coughing and shortness of breath even made it difficult for Catherine to walk her dog or enjoy her hobbies. Medication alone could not keep her lungs clear and the accumulated



## TGH celebrates success

*Toronto General Hospital recently celebrated its 30th anniversary of the world’s first successful lung transplant, performed on November 7, 1983 by Dr. Joel Cooper and his transplant team. Since that time, the hospital continues to pioneer new methods and techniques to prolong and improve the lives of patients who need life-saving lung transplants to survive.*

*Other historic milestones in transplantation surgery at TGH include:*

- 1986: first successful long-term double lung transplant
- 1988: first successful long-term double lung transplant for cystic fibrosis

## Did you know?

- In 2012, 194 lung transplants were performed in Canada.
- In Ontario, 86 people are waiting for lung transplants.
- Wait times for lung transplant surgery are influenced by organ availability, a candidate’s blood type and other factors. In Canada, the average wait for lung transplant surgery is about six to eight months.
- Just 25 per cent of Ontarians have registered their consent to save lives through organ and tissue donation.

mucus made her vulnerable to serious lung infections.

Catherine’s doctor told her about a new drug-free device called the Aerobika OPEP. A study conducted by Robarts Research Institute found patients reporting better mucus clearance and exercise tolerance, less coughing and breathlessness, and overall improved quality of life. The made-in-Ontario innovation has been recognized internationally with Medical Device Excellence Awards for innovation, patient benefits and improvement to the healthcare system.

Catherine, using the Aerobika for six months, noticed a significant improvement in ease of lung clearance after only weeks. “And I haven’t had a serious lung infection since I began the treatment,” she says. “It’s wonderful to have a drug-free option to help me breathe.”

*The Aerobika OPEP is available behind the counter at retail pharmacies across Canada. Learn more at [www.aerobikaopep.com](http://www.aerobikaopep.com)*



## THE COMMON CHALLENGES OF UNCOMMON DISEASES

**G**ord Burwash, 73, knew that something wasn't right eight years ago when he was on a vacation with his wife. He was having trouble carrying his suitcase and walking up stairs.

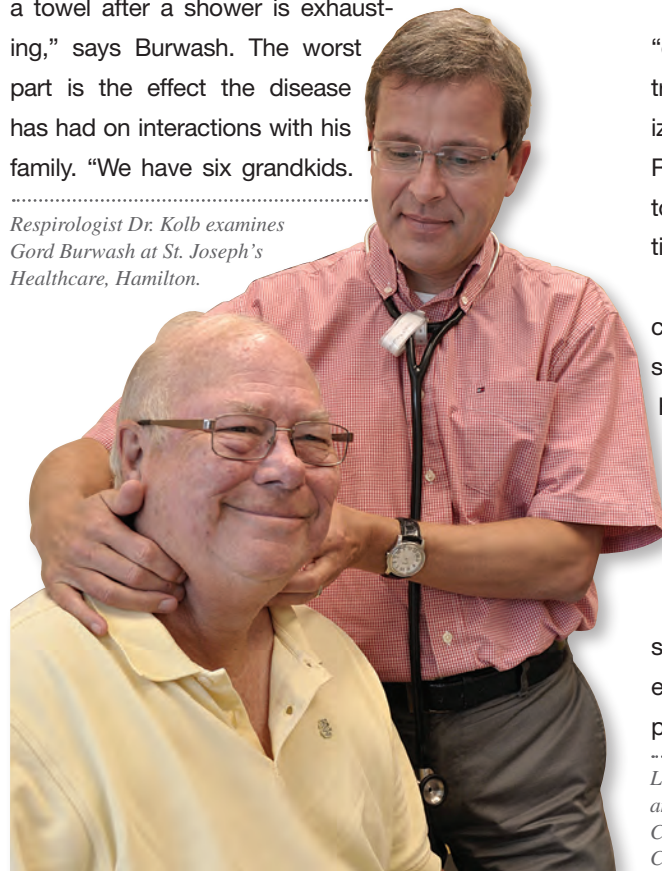
His physician thought he might have pneumonia but it soon became evident that something else was happening. Burwash was sent to see Dr. Martin Kolb, a respirologist at St. Joseph's Healthcare in Hamilton.

He was diagnosed with idiopathic pulmonary fibrosis (IPF), a rare condition that causes

progressive, irreversible scarring of the lungs. Most IPF patients die within three to five years.

Eight years after his diagnosis, Burwash says that he is glad to be alive, even though IPF has made life difficult. A retired school principal, he was once very active but now even small tasks are a challenge. "Drying off with a towel after a shower is exhausting," says Burwash. The worst part is the effect the disease has had on interactions with his family. "We have six grandkids.

Respirologist Dr. Kolb examines Gord Burwash at St. Joseph's Healthcare, Hamilton.



*Raising awareness in the physician community is vital.*

We used to kick a ball around, but now I can't play with them and that really hurts."

Roger Chandler's experience with IPF is somewhat different. He was diagnosed seven years ago, at age 60, when scarring on his lung was detected during his annual physical. "It was very challenging to accept that this disease had taken control and that I may not make it to 80," says Chandler.

A few months ago, however, he started taking the only available medication approved for IPF, which

has been proven to slow disease progression and extend life, and the outlook has brightened considerably. "I know it is not a cure but I certainly feel that the medication has already started working for me," says Chandler. "I cycle with a group and I used to trail at the end – now I'm up at the front. It's really changed my life."

Unfortunately, many people with IPF and other rare or "orphan" diseases, miss out on potentially life-changing treatments because they don't have access to specialized care or can't afford the high cost of treatments. Rare diseases receive little research funding compared to more common conditions and drugs can be prohibitively expensive.

"We're fighting an uphill battle to get attention in a competitive field," says Dr. Gerard Cox, head of clinical services at the Firestone Institute for Respiratory Health. He says young researchers and clinicians avoid specializing in pulmonary fibrosis and IPF because of the limited research funding. The infrastructure and expertise needed to treat rare lung diseases are not available in smaller communities.

IPF also presents challenges because it develops slowly and patients are often not diagnosed early enough, says Dr. Kolb. "Raising awareness in the physician community is vital," he says.

L-R: Gamma-Dynacare SVP Scott Hickey; Breathing as One ambassador Dr. Dawn Bowdish; Gamma-Dynacare president and CEO Naseem Somani; and Ontario Lung Association president and CEO George Habib.

## Philanthropy at work

Each year, employees at Gamma-Dynacare Medical Laboratories nominate charities that are important to them and then vote to choose the company's "lead charity". This year, they chose The Lung Association and its Breathing as One Campaign for the \$25,000 corporate donation.

"The Lung Association and Gamma-Dynacare are a natural fit," says Scott Hickey, vice-president of corporate communications and public affairs with Gamma-Dynacare. The company's social responsibility strategy is driven by its corporate mission to provide information, impact lives and care for people. "Each year, we select an organization that promotes health and wellness, has a national reach, has a strong connection to our employees, and it's typically something that is underfunded, to make the biggest possible impact," says Hickey.

"We know that The Lung Association is laying the groundwork for a new area of research," he says. "We think that's really innovative".

Another major supporter of the Breathing as One Campaign, Transamerica Life Canada, a national insurance company, uses its own mortality data to guide where its charitable dollars go. "What was rather eye-opening was the rate of lung cancer deaths among Canadians," says Glenn Daniels, senior vice-president, general counsel and corporate secretary, and co-chair of the company's corporate giving committee.

The company supports organizations that conduct research to prevent and eliminate diseases such as heart disease and stroke, diabetes and cancer. Daniels hopes that the company's \$20,000 investment will help to reduce the heavy human toll of lung cancer. "We see research as the first step," he says. "The Lung Association is making great strides in that regard."





# A PROUD HISTORY OF SUPPORTING LUNG HEALTH

At the beginning of the last century, tuberculosis (TB) was a greatly feared disease whose harmful effects on children seemed particularly cruel.

It was in December, 1903 that a postman named Einar Holboell was working late out on the outskirts of Copenhagen, sorting great piles of Christmas mail. As he moved around among the mailbags, he paused to look out the window, catching sight of a ragged little girl and boy. He had an idea – to affix an extra stamp to every letter and parcel, with the money raised through this unique effort dedicated to helping the children whose lives were touched by this terrible disease.

The following year, the very first Christmas Seals went on sale. The campaign was even more successful than Einar Holboell allowed himself to dream. With funds raised through the Christmas Seals campaign, two hospitals were built to treat children with TB. It marked a turning point in the treatment of this disease because it was the beginning of a movement that saw ordinary citizens taking a role in fighting an infectious disease that was the leading cause of death around the world.

In 1907, Christmas Seals crossed the Atlantic to the United States, and the following year, the idea reached Canada as groups in Toronto and Hamilton embarked on campaigns to support hospitals being built for TB patients. Year by year, the tradition grew as cities across Canada used the Christmas Seals campaign, not only to raise money, but also to create awareness that TB could be treated.

At first, the money was used to build badly needed sanatoriums. Later, the focus shifted to TB prevention. Although it is no longer the threat it was even 50 years ago, there are still about 1,500 new cases

in Canada every year. It is for this reason that research into TB prevention and cure remains a focus of The Lung Association.

Today's Lung Association, however, has a far bigger mission. As the recognized leader, voice and primary resource to enable all people to breathe with ease, we're in the vanguard of a movement, working to improve the prevention and treatment of lung diseases that make breathing difficult for more than 2.4 million Ontarians. In the process, our research focus has moved well beyond TB to include asthma, chronic obstructive pulmonary disease, lung cancer and many other lung diseases.

The modern lifestyle breeds dangerous pollutants – environmental toxins, allergens and chemicals that attack our lungs and damage

our airways. Even inside our own homes, radon and mould pose hidden risks. Lung disease has become one of the key health and economic challenges facing our province, costing us dearly in terms of

quality of life and economic well-being. We are collectively responsible for creating the breathing breakdown, and so we need to come together to create the breathing breakthrough.

Breathing as One is a new national fundraising campaign that will support The Lung Association's innovative research effort – the National Respiratory Research Strategy. This collaborative strategy will push beyond the traditional boundaries of lung research, leverage new knowledge, attract the brightest medical minds and create the highest standards of treatments.

With your support we will reduce risk, discover cures, save lives and improve the quality of life for all those who struggle to breathe. It's time to raise our collective voice and shine a spotlight on the growing challenges of lung disease.



WE'VE BEEN HOLDING  
OUR BREATH FOR TOO LONG.  
WILL YOU HELP US BREATHE?



To support life-saving lung research,  
please call: 1.888.344.LUNG (5864)  
or donate online at [www.on.lung.ca](http://www.on.lung.ca)

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# SAVE YOUR BREATH!

Take the Lung Health Check! If you, your child or other family member have any of these symptoms, please contact your health-care provider. Any questions? Call the Lung Health Information Line at 1.888.344.LUNG (5864)

Get frequent

colds

that

last longer

**Wheeze?**

Snore loudly?

than other people's?

CHEST TIGHTNESS?

feel sleepy during the day?

...chest pain?

Briefly STOP BREATHING while SLEEPING?

zzz... Get tired after a night's sleep?

Cough up blood?

**Feel short of breath?**

Wake up in the night coughing, wheezing, short of breath or with chest pain?

