



**PULSE—WORLD COPD NEWS:** HIGHLIGHTS OF NEWS RELATED TO LUNG HEALTH .....3



**AN EMERGING PROBLEM:** UNPROVEN STEM CELL THERAPY..1



**COPD PEOPLE:** PHYLLIS ROSEN WORKS THE POLLING STATION DURING ELECTIONS.....7

# Living with COPD

## Let's Boogie: The dance class for people with COPD

**“I have never seen such joy in this class. Everyone was having so much fun,”** said Meeran Manji, Director of Toronto Western Hospital's Pulmonary Rehab clinic. What prompted her response was a “COPD and dance class” that had just ended.

The class is an applied dance program that is investigating the effectiveness of dancing on physical fitness, quality of life, balance, anxiety and depression. This is a pilot program from West Park Healthcare and the University of Toronto, led by Dr. Dina Brooks. The facilitators at the Toronto Western Hospital event were Miriam Schacter, RP and Robin MacPhail-Dempsey. Both facilitators are experienced dance instructors who specialize in working with people with chronic illnesses.

“COPD dance” is not what one would first imagine. A lot of the dancing is done in a sitting position. The dance movements incorporate both large reach and small reach gestures. There are a variety of routines, all set to music. The music is age appropriate and most of the songs were very familiar to the pulmonary rehab group in attendance.

In spite of the fact that you are sitting for a major portion of the program, at the end of the 40

Continued on Page 6

## Chronic Obstructive Pulmonary Disease

### An emerging problem

**U**nproven stem cell treatments for lung disease are those that have not yet been adequately or fully tested for safety and effectiveness (how well they work). The best way to test potential stem cell therapies is through clinical research trials that have to follow certain rules. These rules are set by national regulatory agencies such as Health Canada\* and the U.S. FDA (Food and Drug Administration) to make sure that the treatments are tested following proper scientific methods without any conflict of interest.

#### What are stem cells and how can they potentially be used in medicine?

Stem cells are undifferentiated cells that have the ability to become specialized cells. They also are able to make more copies of themselves. There are different types of stem cells including those found in embryos (embryonic stem cells) and those produced in the laboratory by treating normal adult cells, such as those from the skin or muscle, to become stem cells (induced pluripotent stem cells). In addition, researchers are learning that every organ in the body has a small number of cells that serve as organ-specific stem cells that work to replace or repair damaged tissue. It is possible that each of these types of stem cells may one day be used to treat different human diseases. One example of successful use of

Continued on Page 5

### Ask Dr. Bourbeau

Jean Bourbeau is a respirologist and full professor in the Department of Medicine and Epidemiology and Biostatistics, McGill University, Montreal



**Q** I was wondering if anyone with COPD has experienced swollen feet. Could it be caused by my COPD medications?

**A** In COPD patients, swelling of the legs, ankles, and feet can be related to prednisone treatment although it may also indicate that the patient has developed a type of heart failure called cor pulmonale, or right ventricular failure. Patients with swollen feet should inform their physician and be evaluated.

Continued on Page 2

Continued from Page 1

**Q** Is there any truth to the report that the use of statin drugs can reduce exacerbations, hospital admissions and prolong life expectancy in COPD patients?

**A** From a recent randomized clinical trial, the statin drugs had no effect in reducing severe exacerbations or hospitalizations. Accordingly, the highest level of evidence doesn't support the use of statins in COPD in the prevention of exacerbations. However, statins are well-known and widely prescribed for their lipid-lowering effects and improved outcomes related to cardiovascular diseases, including mortality.

**Q** I was recently diagnosed with COPD. My oxygen levels are good during the daytime, but just saw my doc and got the results of a night time oxygen test. Up and down, but approximately three hours total of below 90%. Probably when I'm dreaming, said the doc. Now he wants me to use oxygen at night. I hate it, and not really sure I need it. What do you think?

**A** Sleep-related non-apneic oxygen desaturation often occurs in patients not qualifying for long-term oxygen therapy and is considered by many physicians as an indication for providing nocturnal oxygen therapy. This perceived indication stems from the suggestion that the natural progression of COPD to its end stages and death may be dependent upon the severity of desaturation occurring during sleep. However, the clinical benefits of nocturnal oxygen therapy have yet to be confirmed.

**Q** I am supposed to have an Arterial Blood Gas test performed. Is this commonly used for COPD testing?

**A** Arterial blood gases (ABGs) are an important routine investigation to monitor the acid-base balance of COPD patients. They may help indicate the severity of a condition and help to assess treatment such as long-term oxygen therapy.

**Q** I'm being considered for lung volume reduction surgery (LVRS). Is this a worthwhile procedure?

**A** Lung volume reduction surgery has been shown to help improve breathing ability, lung capacity, and overall quality of life in very selected COPD patients. The effectiveness of this surgery depends on the location or extent of the diseased tissue, as well as the patient's exercise tolerance and ability to tolerate surgery. In some cases, the optimal procedure is clear but in others, the optimal choice may not be so clear. A thorough understanding of the indications, contraindications, risks, and benefits of the LVRS, as well as the patient's goals and preferences, should guide the decision-making process.

**Q** My husband has had COPD for 18 years. His FEV-1 is in the Very Severe category. He is having more frequent exacerbations than years ago and he needs to take prednisone when he feels an exacerbation coming on. He becomes very moody, angry, and has hateful outbursts that come out of nowhere and are usually directed at me. It's destroying our marriage. Are there any recommendations for medications to counter the mood swings of prednisone?

**A** Not everybody has mood changes while taking prednisone, and most of the time the effects are considered "mild." Changes in mood—if caused by prednisone—usually go away once a person stops taking it. Talk to the doctor about the potential for mood swings, and find out what should be done.

**Editor's note:** For more information on Dr. Bourbeau's Living Well with COPD program visit [www.livingwellwithcopd.com](http://www.livingwellwithcopd.com)

To preview the first of their new COPD online learning modules "Preventing your COPD Symptoms" visit: <https://youtu.be/0hp2kly7W7U>

Dr. Jean Bourbeau is director of the Center for Innovative Medicine (CIM) of the Research Institute of the McGill University Health Centre (MUHC) and director of the Pulmonary Rehabilitation Unit. He is past president of the Canadian Thoracic Society (CTS) and is a member of the scientific committee of GOLD. He has a research chair in COPD, Living Well with COPD, and online course lines.

*We invite your questions. Please mail questions to Ask Dr. Bourbeau c/o COPD Canada, 555 Burnhamthorpe Rd., Suite 306, Toronto, Ont. M9C 2Y3. Or you can e-mail questions to: [AskCOPDCanada@gmail.com](mailto:AskCOPDCanada@gmail.com)*

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# Pulse: News about COPD

## Outpatient antibiotic prescribing unchanged

■ **St. Louis/** Over the last three years outpatient antibiotic prescribing in the United States remained unchanged despite efforts to limit inappropriate antimicrobial use, according to Michael J. Durkin, MD, MPH, an assistant professor of medicine at the Washington University School of Medicine, and colleagues. The data show that further efforts are needed to control antibiotic use in the context of resistance, the researchers wrote in *Infection Control & Hospital Epidemiology*. “The findings of this study are concerning but more than anything, they give us important insight into the ongoing challenges of getting health care providers to change their prescribing habits to help prevent antibiotic resistance,” said Keith Kaye, MD, MPH, president of the Society for Healthcare Epidemiology of America. “While the resources and investments made to identify and raise awareness regarding overuse of antibiotics are important, they are not enough.” The most commonly prescribed antibiotic drugs were amoxicillin, amoxicillin/clavulanate, azithromycin, cephalexin and ciprofloxacin.

 <https://tinyurl.com/y9ncvpt2>

## Effects of household air pollution on respiratory health


■ **Albuquerque, N.M./** More than 2.8 billion people worldwide use solid fuel for cooking, with many more using solid fuels for heating homes, according to a report published recently in the *European Respiratory Journal*. Combustion of solid fuels in inefficient stoves in poorly ventilated homes leads to household air pollution (HAP). Solid fuels include wood, charcoal, crop residues and animal dung (collectively referred to as biomass fuels), and coal. With inefficient combustion of these solid fuels, a complex mixture of carbon-based particles, inorganic particles and irritant gases is generated, which shares some characteristics with that of tobacco smoke and includes carcinogens. Observational studies demonstrate strong associations between exposure to HAP and childhood respiratory tract infections, COPD, lung cancer, cataracts and low birthweight of children, with limited evidence supporting associations with cardiovascular disease. People exposed to household air demonstrated greater small airways fibrosis but less emphysema compared with cigarette smokers.

 <https://tinyurl.com/ybprp6ru>

# Pulse: News about COPD

## Low back pain in people with COPD

■ **Milan, Italy/** A recent study published in the International Journal of COPD analyzed gastroesophageal reflux disease (GERD) and low back pain (LBP) in patients with chronic obstructive pulmonary disease (COPD). The researchers sought to understand the reasons for these comorbidities. The considerations of the authors are based on the functions and characteristics of the respiratory diaphragm that are not always considered in patients. They reported that between 51% and 88% of patients with COPD have at least one comorbidity such as cardiovascular pathologies, arthritis, osteoporosis, diabetes and chronic pain. The mechanisms that cause these comorbidities and the precise relation to the presence of COPD are not entirely clear. Probably, the systemic inflammatory nature of COPD favours the natural course of these comorbidities. GERD is a comorbidity often found in these patients. It has the potential of exacerbating the symptoms of COPD while increasing the number of events requiring hospitalization.

 <https://tinyurl.com/ydx24wkx>

## Duration provides stronger risk estimate than pack-years

■ **London /** Smoking burden is frequently measured in pack-years, but the relative contribution of cigarettes smoked per day versus the number of years smoked toward the development of structural lung disease, airflow obstruction and functional outcomes is not known. The researchers analysed cross-sectional data from a large multicentre cohort (COPDGene) of current and former smokers. Primary outcome was airflow obstruction (FEV1/FVC). Generalized linear models were estimated to compare the relative contribution of each smoking variable with the outcomes. They estimated linear trends by cigarettes/day, smoking duration and pack-years. Results were based on 10,187 subjects. The researchers concluded that smoking duration alone provides stronger risk estimates of COPD than the composite index of pack-years. They also stated that cigarette smoking is the strongest risk factor for COPD. The study was recently published in the British Thoracic Society's journal Thorax.

 <https://tinyurl.com/y9kcbmwp>

## An emerging problem

continued from page 1

stem cells is the use of bone marrow stem cells (hematopoietic stem cells) to treat certain types of leukemias and lymphomas. However, there is much not yet known about all stem cell types and how they work. Much more research is needed to safely and effectively use these in people with other diseases. There are a number of areas of active research going on. One example is the research into finding a way to stimulate organ-specific stem cells in the body to repair diseased tissue. Another area of research involves isolating stem cells and stimulating them in the laboratory to become specialized cells for use in transplantation.

### Are stem cell treatments an option for lung disease?

In theory, yes in the future. In many lung diseases, cells that make up the respiratory system are either lost or do not function properly. A stem cell treatment that restores lung cell function might be able to reverse or even cure some lung diseases. As of now, there are no proven stem cell treatments for any lung disease.

### Who offers unproven stem cell treatments?

Unfortunately, there are hundreds of clinics and other groups offering unproven stem cell treatments in the U.S. A frequent method that they use to treat lung disease involves removing cells from a person's fat or bone marrow and giving the cells back to the person through his or her bloodstream. These approaches have not been proven to work and are not FDA regulated or approved as accepted treatments for any type of lung disease. This means that the necessary clinical research trials to make sure that these treatments are safe and effective have not been done. Unfortunately, this does not prevent them from being offered despite unknown risk or benefit.

### Do unproven stem cell treatments work for lung disease?

There have been promising studies in animal models of lung diseases. Yet, there is no reliable evidence that stem cell treatments are effective for any lung disease. To date, there have been some legitimate clinical trials, approved and regulated by the FDA or by appropriate regulatory agencies in other countries. These have been done for a number of lung diseases including COPD, acute respiratory distress syndrome, idiopathic pulmonary fibrosis, and

pulmonary hypertension. These studies have used several different types of stem cells including mesenchymal stromal cells and endothelial progenitor cells. Initial results suggest that the stem cells used appear to be safe over a short-term period. However, further follow-up is necessary to ensure long term safety. Importantly, none of these studies have shown any beneficial effect in any lung disease tested so far.

### Could unproven stem cell treatments be harmful?

Yes, these treatments can be potentially harmful. Potential risks include cell embolism (stem cells clotting in the lungs) and the cells causing abnormal growth including tumors. In addition, a number of clinics are giving treatment in ways that do not meet normal standards of sterility (to prevent infection) and safety.

### What do pulmonologists say about unproven stem cell treatments?

Pulmonologists (lung specialists) familiar with the issues of unproven stem cell therapies for lung diseases are opposed to this approach. However, many lung specialists are also not yet familiar with the field. The American Thoracic Society (ATS) Stem Cell Working Group as well as other professional societies have developed educational resources for doctors as well as for patients and their families. All involved are strongly encouraged to read these resources to learn more about stem cells and their use. Patients and doctors should take time to learn all they can about the issues surrounding unproven stem cell therapies.

### What do lung disease foundations and patient advocacy groups say about unproven stem cell treatments?

A growing number of national and international respiratory disease societies and patient advocacy groups have taken strong positions against unproven stem cell therapies. This is also true for the leading stem cell scientific societies who do not support use of unproven stem cell therapies at this time. All of these groups are trying to educate patients, families, caregivers, and health care professionals about the

Continued on Page 6

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- If you are not yet a member, [sign-up](#), it is Free!

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## An emerging problem

continued from page 5

potential dangers of treatments.

### I suffer from lung disease and I am interested in stem cell treatments. What should I do?

First, talk to your health care provider about current treatment options. These may include new medications that can slow down the progression of the disease. If they are unfamiliar with the stem cell field, refer them to the available educational resources that you are reading. You need to carefully read all you can as well. Particular points to consider and to discuss with your health care provider are:

- 1) whether there is any scientific evidence to support the proposed treatment approach for your lung disease; and
- 2) whether the offered treatment has been studied in a legitimate clinical trial.

### How can I find if a stem cell treatment for lung disease is part of a legitimate clinical trial?

The U.S. government compiles a list of all registered clinical trials in the U.S. and abroad, including clinical trials for stem cell treatments. This can be easily accessed on the website [www.clinicaltrials.gov](http://www.clinicaltrials.gov). You can use keywords such as “stem cells” and your lung disease diagnosis such as “chronic obstructive pulmonary disease,” “cystic fibrosis,” or “pulmonary fibrosis” to find clinical trials. However, you should be aware that some clinics offering unproven stem cell treatments register

their treatments in the ClinicalTrials.gov database but have not gone through the proper approvals or inspections. The U.S. government is currently working to tighten the requirements for any potential new therapy or clinical trial to be legitimately listed on the database. Importantly, people who are research subjects should not be charged for participation in clinical trials. You should fully discuss any information you find on the [clinicaltrials.gov](http://clinicaltrials.gov) website with your health care provider. The Canadian Clinical Trials\* database can be accessed through the following web site:

<https://www.canada.ca/en/health-canada/services/drugs-health-products/drug-products/health-canada-clinical-trials-database.html>

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For more information:  
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## Let's Boogie

continued from page 1

minutes you can definitely feel that you got a work out. The dance-based exercising is mixed in with joy, singing and laughing. One of the program sessions has you gesture dancing as though you are conducting an orchestra. Another has you going through the motions of playing baseball. You go at your own pace. However, this group of 30 patients enthusiastically dove in. “Riding on the freeway of love in my pink Cadillac,” indeed.

The entire “Let’s Boogie” program is comprised of 16 classes. Participants explore different dance styles such as ballroom and social dancing, ballet, jazz, contemporary, elements of free dance/authentic movement/contact dance, collaborative choreography, and mirror-work. Each class includes seated and standing work, with two rest and water breaks and, loads of fun.

### For more information on the program:

<https://tinyurl.com/ydxpmjrp>

### If you think you might be interested in participating in this dance/exercise study contact:

Adnan Wshah  
[adnan.wshah@mail.utoronto.ca](mailto:adnan.wshah@mail.utoronto.ca)

—HR



## COPD Canada Twitter

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For more information contact: Henry Roberts  
email: [henry.copdcanada@gmail.com](mailto:henry.copdcanada@gmail.com)  
telephone: 416-465-6995



# COPD people

## Phyllis Rosen

Phyllis was born in Beeton, Ont., a small town of about 500 people located 45 miles north of Toronto. In her teens she moved to Toronto because there was no work in Beeton. Her first job in Toronto was with the Laura Secord company. She worked in the manufacturing plant making chocolates. After a relatively short stint there she moved on to the Bank of Montreal. Later, she joined her husband in the rare coin business. Their company, which he founded, was called the Toronto Coin Centre, located on Queen Street. The Toronto Coin Centre was primarily a mail order coin exchange for rare coins as well as military badges. They worked together for 46 years, until his passing 13 years ago. Phyllis has three children, all sons. Two are in sales, the middle son is a teacher in Los Angeles. Her niece Debbie has moved in with her and is a great companion who helps Phyllis lead an active life. Debbie accompanies Phyllis around town while shopping and for trips to and from pulmonary rehab classes. They were recently in Clearwater, Florida, where they have a number of friends who are Canadian expats. "They're so good to us."

### Was your husband a numismatist?

**A**t the time he was. I learned a lot about coins through the business but it's been a while since he passed. I haven't been keeping up on it.

### When did you realize there was something wrong with your health?

When I turned 50 my husband took me on a trip to Europe. We flew from Toronto to Copenhagen, Denmark. Then we went to Sweden and from there we took a train to Germany. We also went to Vienna, Austria and ended up in Venice. I had the worst time breathing so we came home early.

### Did you get medical help when you got home?

I saw my family doctor right away. His diagnosis was asthma. So, I had asthma for 20 years. Eventually my condition worsened so I was sent to a respirologist who said that I don't have asthma, that I have emphysema. At Toronto Western Hospital I saw a second respirologist who confirmed that I in fact have emphysema, COPD. That diagnosis was about three years ago.

### Were you a smoker?

I sure was. I smoked for 50 years. I started smoking when I was eighteen. Back then, smoking was like being a movie star. The women would smoke in the movies using those long cigarette holders. They looked so glamorous.

### Did you use a cigarette holder?

No, but I did feel a bit glamorous smoking a cigarette. You were right with it.

### Were you a partier?

Nope. I never drank. I would even avoid New Year's Eve parties because of all the drunks.

### You live near [the former location of] Honest Ed's on Bloor Street. Did you ever meet Ed Mirvish?

Many, many times. Great man. He was so good to the community. Free turkeys at Christmas. A great big birthday party in July every year. It seems that all of Toronto came to the birthday party. Free hot dogs, hamburgers, french fries, soft drinks and cake. The kids loved it.

### Are you retired?

Yes. But I still help out with elections. I work in the local polling station during both provincial and federal elections. So, I'll be starting up soon as we have a provincial election coming up in June.

### Are you involved in the advanced polling process?

We make sure that people can get their votes in. Sometimes, for voters who can't get out, we'll send two people to their place with a ballot. The voter seals the ballot, which is then returned to the polling station.

### Are you a religious person?

No, I'm not. I should be I suppose but I'm not. I think it's great for people who have found religion.

### What's your favorite food?

I'm a traditionalist. I like roast beef with gravy, potatoes and any vegetable. I like most vegetables.

### How's your emphysema now?

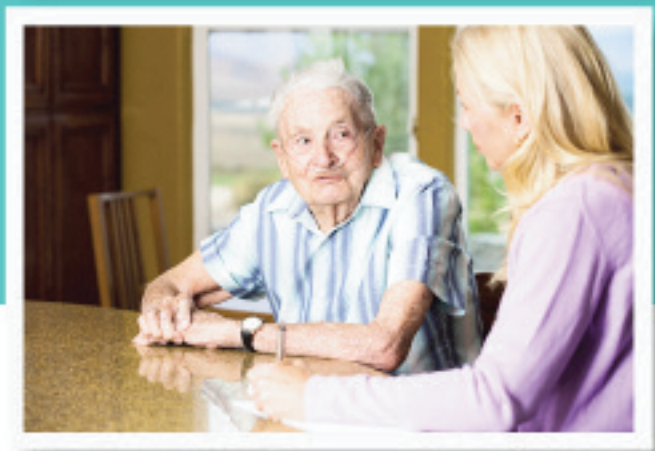
It's stable. My spirometry results haven't changed over the last two years. My doctor says I need to slow down though. He says I race around too much. I've always been a speedy person.



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