The
# Pulmonary Paper

*Dedicated to Respiratory Health Care*
March/April 2018 Vol. 29, No. 2

# compassion

"People will forget what you said, people will forget what you did, but people will never forget how you made them feel."

Maya Angelou

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We are hiding The Pulmonary Paper logo on our front cover. Can you find it?

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*Compassion motivates people to go out of their way to help others and therefore themselves!*

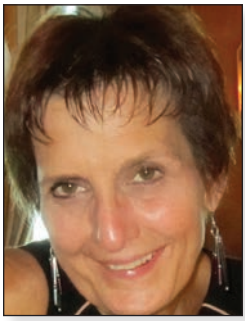
*Joy Recla enjoys traveling with the Sea Puffers!*

## Feeling Compassion

Before we can feel compassion for others, we first must feel compassion for ourselves. Self-compassion frees you of feeling guilty or unworthy. It lets you live free of judgment. You are not being self-indulgent by allowing yourself to forgive. Forgive yourself for past smoking or other unhealthy behaviors. Live today without shame.

If you are feeling less than compassionate toward someone, try to recognize what you have in common. When you are meeting someone for the first time or when you are with an old friend or family member, try and think: Just like me, this person is seeking happiness. Just like me they are trying to avoid suffering. Just like me they have known sadness, loneliness and despair. Just like me, they are seeking to fulfill their needs. And just like me, this person is learning about life.

True compassion and non-judgment is hard work. You do not know what someone may be going through. The story of a father and his three children on a bus shows us this. The father was lost in his own thoughts, and the kids were loud and disruptive to the other passengers. A lady leaned over to the father and said, "You really need to parent your children better. They are so unruly." The father, shaken from his thoughts, says, "I'm so sorry. Their mother, my wife, just died and we are returning from her funeral. I think we are all a little overwhelmed. I apologize."



*"Wisdom, compassion, and courage are the three universally recognized moral qualities of men."*
*Confucius*

# Editor's Note

**The definition of** compassion is the sympathetic pity and concern for the sufferings or misfortunes of others. It literally means to "suffer together." Many times we are caught up in our own concerns that we lose sense of what others around us may be coping with. Try not to make it all about you.

I think we would all like to be remembered as a person who was kind and thoughtful but this does not happen without effort. Articles have been written discussing how compassion is not being instilled in our children. Some suggest meditation may help us see life from a different perspective. Stay involved with others. With lung disease, it is easy to think you can't do something because you will get short of breath but don't use that as an excuse to avoid social interaction. Getting short of breath is uncomfortable but you will recover. Using pursed lip breathing and increasing your oxygen flow when active puts you in control. It might take a little extra time to get from the parking lot into the restaurant, but you are sure to enjoy a meal with family and friends when you get there! Don't avoid it.

Volunteer at your local library. If you have a hobby you enjoy, share or teach it to young people. Helping others takes the focus away from worrying about your own situation and will only make you feel happier in the long run!

Our friend John Goodman, who has inspired us with many articles in *The Pulmonary Paper,* recently lost his son Jason to cancer. Jason, a respiratory therapist like his Dad, leaves happy memories for his family to cherish. They are all in our hearts.

*Jason Goodman, left, shares a hug with his Dad.*

*Norma Jean, left, and Holly enjoy each other's company on a recent trip!*

*Dr. Michael Bauer*

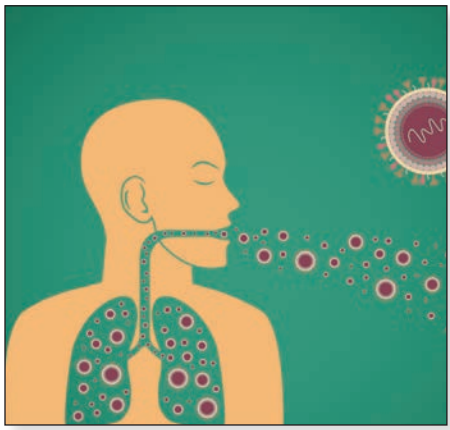
# Calling Dr. Bauer …

**Dear Dr. Bauer,**

**I was told I have "hypersensitivity" lung disease and am unsure what this means! Thanks for any help in understanding.**

**Evelyn P., Maryland**

**This is a** specific type of interstitial lung disease (ILD) that is more accurately called "hypersensitivity pneumonitis" or HP. HP is caused by an allergic reaction that occurs in the lung when certain organic proteins are inhaled from the environment. I like to describe it as "poison ivy" that takes place in the lung tissues. This is a very different type of allergy compared to asthma. Signs and symptoms of HP may include fever, chills, muscle or joint pain, or headaches, cough, chronic bronchitis, shortness of breath, weight loss, fatigue, and/or fibrosis of the lungs. HP results in dry cough, fever, and lung scarring. Asthma symptoms are typically wheezing and cough with mucus.



Where I live in upstate New York, I see farmers occasionally presenting with "Farmer's Lung", an allergic reaction to inhaled dusts commonly seen in the barn. Many causes of HP have been described. A bad reaction to bird dander and droppings from indoor parrots and parakeets is a classic HP. Others include dust associated with grain and flour processing, lumber milling and construction, and veterinary work and animal handling. Diagnosis is best made by your doctor taking a thorough medical history from you. Sometimes a blood test is helpful.

The primary treatment of HP is to stop the exposure! This means the person needs to use an appropriate dust mask with potential exposure or even better – stop working in the environment or get the offending agent out entirely. Allergy-causing bacteria and fungus can thrive in stagnant water so be sure to remove any standing water around your home. Immediately repair any water damage including removing water-damaged carpeting, furnishings and drywall. Take efforts to keep the humidity in your home and work below 50 percent. Prednisone or other steroids can quicken recovery. HP should be a preventable and very treatable disease.

**Questions for Dr. Bauer? You may write to him at The Pulmonary Paper, PO Box 877, Ormond Beach, FL 32175 or by email at info@pulmonarypaper.org.**

CHEST FOUNDATION

Allergy & Asthma NETWORK

COPD FOUNDATION

FOR PATIENTS

## Get the facts about **GENERIC DRUGS**

# MYTHS BUSTED

**Every brand-name drug has a generic version.**

**FACT:** Not all brand-name drugs have generic versions. Due to the high costs of research and development, all new drugs are protected by patents and can only be sold for a period of time by the company that made them. When these patents expire, other companies are then allowed to seek FDA approval to develop and sell a generic version of the drug.

**You need to take more of a generic drug than a brand-name drug.**

**FACT:** All generic drugs must be the same in terms of how they work and how much must be taken compared with brand-name drugs. There is no evidence that brand-name drugs work better than other drugs.

**Generic drugs are lower quality than brand names.**

**FACT:** The FDA requires generic companies to meet manufacturing standards that are the same as brand-name drugs.

**Brand and generic pills must always look the same.**

**FACT:** More often, brand-name pills and generic pills look different despite having the same active ingredients.

**Generics made in other countries are the same as generic drugs made in the United States.**

**FACT:** Not all generic drugs are the same from country to country. The United States has strict requirements for product testing and manufacturing of generic drugs. Requirements in other countries may be different.

Learn more about generic drugs by visiting **chestfoundation.org/generics**

These patient education materials, including infographic, and other collateral pieces are generously supported by Mylan.

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*Mark Mangus, RRT*
*EFFORTS Board*

# Ask Mark …

**My biggest problem with my lung disease is getting up stairs. Do you have advice on how to accomplish this a little easier?**

**Vicky M., Florida**

**Mark explains,** Climbing stairs is one of the most challenging forms of exertion for most folks with breathing limitations. I know an exercise that may help you and others who wish to strengthen their leg muscles and build endurance. One method I have taught for years is simply stepping up and down from a six or eight-inch step, repeatedly, for an increasing number of repetitions or a certain length of time. Increase the time as strength, endurance and tolerance will allow. This exercise will go a long way toward helping to make actual stair climbing more manageable.

Start out with a few repetitions – even five is not too few – and try it several times a day. Gradually add repetitions until you can step up and down 50 times, using each leg to lead. As you step, lead with the right foot for half the repetitions and switch to your left foot for the other half. This will allow equal strength-building between the two legs.

Soreness with exercise is typical for folks who have poorly conditioned muscles that are put to work doing exertionally demanding tasks. The only way the soreness will reduce in severity and stop is through exercise. You place repeated and increased demand on your muscles. Go slow, easy and gently. Gradually over time they will improve.

**Jerry from EFFORTS asks what stem cell therapies are FDA approved?**

**Mark replies,** The only FDA-approved application of stem cell therapy in the USA, at this time, is for hematopoetic (bone marrow/blood) treatment purposes. That is what is stated on the FDA website. Very few investigative groups have FDA-approved studies in progress. They can show you their paperwork from the FDA to verify any claim that they are doing FDA-approved research. If a center can't produce this paperwork, they are not FDA-approved.

There are a lot of groups doing "patient-funded" research. Those are the ones who will charge you for treatment and participation. Stay away from

**Mark Mangus RRT, BSRC, is a member of the Medical Board of EFFORTS (the online support group, Emphysema Foundation For Our Right To Survive, www.emphysema. net). He generously donates his time to answer members' questions.**

them. If they truly had a treatment model of reasonably expected potential, they would apply for FDA approval. And, they would also be likely to be able to get funding support from the National Institute of Health.

The snag in getting approval from the FDA, is not only showing the study model truly has potential benefits, but also an appropriate source of stem cells and a method of processing and handling them. Therein lies the difficulty. Many are not obtaining appropriately sourced stem cells and they are also not handling them in a manner that makes them safe, much less potentially effective.

**Twenty years ago,** we printed an article entitled, "Five Ways to Breathe Easier". The advice is still valid and valuable! Those who make proactive choices seem to reduce the severity and frequency of respiratory infections.

**1. Exercise:** The benefits of exercise include better use of oxygen by muscles, increased ability to handle stress and improved ability to ward off infection. A simple home walking program for up to 30 minutes every other day is a good way to start.

**2. Inhaled medications:** 50 to 80 Percent of people using metered dose inhalers do not get the medication's maximum benefits. This is due to improper technique in using the inhaler. Review instructions with your physician or healthcare provider.


**3. Environment:** Avoid or modify environmental insults. Concentrate on eliminating or reducing allergens in the home – dust, mold, dander, etc. Protect the airway when temperatures stay below 40 degrees with a scarf or warming mask. Avoid temperatures above 80 degrees and 60 percent humidity when at all possible.

**4. Breathlessness:** Shortness of breath is the hallmark of chronic lung disease. Learn and practice breathing techniques as pursed lip and diaphragmatic breathing to lessen the effects of breathlessness.

**5. Early treatment:** Early treatment of flare-ups (or exacerbations) is fundamental in slowing the advancement or worsening of a chronic lung condition.

Some symptoms to watch for are:

- Productive coughing (changes in mucus color, amount, odor/taste or consistency)
- Shortness of breath
- Fever
- Inability to sustain nutrition
- Difficulty sleeping

Any or all of these may be warning signs for you to get help.

# Fibrosis File

## Find Support. Give Support. Get Support.

The Pulmonary Fibrosis Foundation (PFF) believes participating in a support group may improve your emotional well-being and have a positive impact on your health by offering you an opportunity to connect with others who are facing similar experiences to obtain practical information, and to receive support. Please visit *www.pulmonaryfibrosis.org/life-with-pf/support-groups* to find a group in your area.

There are many online groups you might get involved in but attending a meeting where you can see people face-to-face is an added benefit! You will also be able to find valuable educational resources at the PFF web site including an hour-long video on Nutrition and Interstitial Lung Disease.

## Dentist Office Mystery

Health officials have identified a group of dentists who died of a mysterious lung disease. A report published by the Centers for Disease Control and Prevention found that nine dentists in Virginia were found to have idiopathic pulmonary fibrosis (IPF) between the years 2000 and 2015. The researchers found 894 people diagnosed with IPF at a medical center in Virginia. Dentists made up just 1 percent of the people documented in the study but about 23 times higher than expected.

Past research has linked IPF to jobs that involve exposure to dust, wood dust and metal dust. Some other suspected causes include tobacco smoke and viral infections.

This is the first study to find a possible association with dentistry and IPF. Dentists and other dental personnel have unique exposures at work. These exposures include bacteria, viruses, dusts, gases, radiation and other respiratory hazards. The likelihood of exposure to dusts and airborne chemicals is less than in the past, but still there for many dentists, particularly if they trained long ago and haven't kept up with environmental and workplace warnings. Experts recommend dental workers wear certified respiratory masks if they are working in any environment that might result in respiratory hazards.

## Fibrosis Research Developments

*The American Journal of Respiratory Cell and Molecular Biology* published a study that suggests increasing the production of lipids in the lungs may help slow pulmonary fibrosis progression and potentially lead to new treatment options. Pulmonary lipids, also called surfactants, play a key role in lung flexibility to help the lung sacs open up when breathing. This suggests that the body's failure to produce lipids, perhaps due to injury or age-related changes, may be a factor in development of lung fibrosis. Scientists are now working on developing a therapy based on these findings to help those with pulmonary fibrosis.

**Using statins to** prevent cardiovascular disease is safe for those with IPF, according to an analysis of trial data on the IPF therapy Ofev (nintedanib). Statin therapy does not contribute to lung function decline or diminish Ofev's effectiveness in IPF, researchers said. Their analysis of data from the INPULSIS trials appeared in the journal *Respiration*.

**A Phase 2** clinical trial showed Reata Pharmaceutical's experimental medication, bardoxolone methyl, significantly improved the exercise capacity of people with idiopathic lung disease (ILD) associated with pulmonary arterial hypertension (PAH)

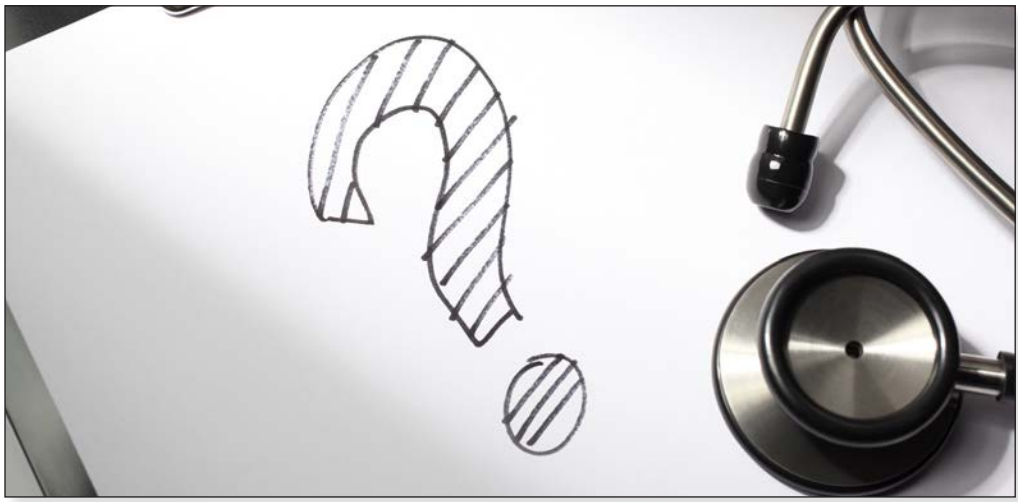
The ongoing LARIAT study (NCT02036970) is evaluating the safety and efficacy of bardoxolone in people with PAH associated with several lung diseases. They include IPF, sarcoidosis, connective tissue disorder, and idiopathic interstitial pneumonia.


**A lung transplant** is the only way to cure IPF. Boehringer Ingelheim's Ofev (nintedanib) preserved the lung function of nine people with IPF waiting for a lung transplant, according to a study in the journal *Respirology Case Reports*. Ofev fights lung tissue scarring. Seven people had lost an average of 7.8 percent of their lung function before starting Ofev. The measure researchers used was forced vital capacity – the amount of air a person can exhale after taking the deepest breath possible. Once Ofev was started, the lung function decline of eight of them averaged only 3.2 percent over 12 weeks.

## Worldwide Clinical Studies

*www.ClinicalTrials.gov* is a database of privately and publicly funded clinical studies conducted around the world. You can find information about how to participate in the studies and those that are currently available. "NCT" is a unique identification code given to each clinical study record registered on *ClinicalTrials.gov*. The format is "NCT" followed by an 8-digit number. To make it easy for people with pulmonary fibrosis, the PFF has established the web site *https://trials.pulmonaryfibrosis.org* that organizes relevant studies for their review.

## Six Dos and Don'ts for Living Well with a Chronic Illness



Our thanks to Charlene Marshall of *www.lungdiseasenews.com*, for an excellent list of "Six Dos and Don'ts for Living Well with a Chronic Illness".

Charlene notes there is no right or wrong way to deal with the diagnosis of a life-threatening or chronic illness, nor are there instructions on how to cope while living with it. Each person's journey with a chronic illness is as unique as they are, and strategies that work for some will not work for others. There is strength in numbers and usually with a little networking, people can find ways of coping from those who are willing to share what's been helpful to them. The hope is that they can apply the experiences of others to their own lives to better cope with their disease as these tips:

**DO Allow yourself time to process all the emotions.** You may feel happy that you have finally found an answer to your symptoms and why you feel unwell. It doesn't mean you are happy with the diagnosis, but having an answer and a subsequent treatment plan brings a sense of a relief. Process all the emotions including anger, guilt, sadness, fear and frustration. There is no right or wrong way to feel and giving yourself time to process all the emotions is important.

**Seek out support from friends, family and colleagues.** As much as it might feel easier to do this alone, living with illness can become overwhelming quickly. Feeling guilty and like a burden are common, but be aware of these feelings and seek out friends and family members who can support you. This will alleviate some of the guilt of frequently asking the same small group of people to support you.

**Embrace your diagnosis as an opportunity to educate: knowledge is power!** Sharing your story may be hard at first, and it will take courage, but often the rewards outweigh the risks of sharing details of your illness. People who care about you will want to jump on board with how they can help raise awareness for a cause that is now dear to them, because you are important to those around you. Raising awareness and educating others is a powerful way to

harness some control back into your life, and you never know who you may touch or inspire along the way.

**Stay off Google!** As tempting as it is to pull up millions of online pages of information about your illness within seconds, it is often unhelpful unless you are seeking a credible source. Sometimes the information online is terrifying and the important thing to remember is that when it comes to your health, your physician or team of specialists are the most knowledgeable and should be your first stop for information.

**DON'T Try to protect others by not sharing your struggles.** This is an incredibly hard lesson to learn, but one that is important. Your struggles are a product of your disease. Protecting others puts them in a position of failure when it comes to helping you: they cannot help you if they don't know the reality of your situation.

**Don't put off asking questions.** Your questions are important, they are valid and they are why doctors are there: to answer your questions and treat your disease. If you have a question, it's important to speak up in a timely manner so that you can manage your disease as effectively as possible.

## Nutrition Tips

People with chronic lung problems must cope with an imbalance between energy supply and energy demand. Metabolic demands are increased due to the work of breathing, and calorie intake often is not enough to meet these demands. The net effect is progressive malnutrition.

You can eat small amounts more frequently to get your required calories. Smaller amounts of food will also help lessen abdominal distention and upward pressure on the diaphragm which can cause shortness of breath. Avoid gas producing foods that will cause bloating. These include beans, broccoli, cauliflower, cucumbers, onions, raw apples, melons and cabbage. You will learn what you can tolerate.

Fats produce less carbon dioxide than does a carbohydrate rich diet. Your lungs won't have to work so hard to get rid of the carbon dioxide.

Do not skip meals even if you don't feel like eating. Drink a liquid breakfast or nutritional supplement in the morning. To save energy, choose foods that are easy to prepare.

Drink 8 to 12 cups of water or non-caffeinated liquids every day to help keep your mucus thin and easy to cough up. If you drink your beverage at the end of the meal, it will prevent you from filling up quickly.

Don't waste energy consuming foods with little nutritional value, such as potato chips, candy bars and soft drinks.

CALL TODAY!

# What POC is Right for Me?

## Main Clinic will match you to a POC that fits you and your needs!

"I am extremely happy with my POC. It gives me the freedom to go places again that you just can't go with oxygen tanks! Courtney was very helpful, knowledgeable and truly matched me to the best POC for my lifestyle. Thank you, Courtney!" **JN, Michigan**

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*Inogen® GS-100*

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*Ryan Diesem*

# The Ryan Report

**Home Oxygen Guru – The $HO_2G$ Pen**

## Innovation in Home Oxygen Systems – Where Is It?

**In the upcoming** May/June issue of *The Pulmonary Paper,* we'll be publishing our guide to portable oxygen concentrators (POCs), which has become an annual feature and one of the more anticipated articles of the year. More and more people are looking for guidance in purchasing home oxygen equipment that will fit their lifestyle while meeting their oxygenation needs. In beginning to prepare for the upcoming issue, I took an assessment of what products will be included this year and realized there hasn't been much new in the last few years, let alone any product that could be qualified as innovative or bringing something new to the table. Numerous POCs were introduced between 2005 and 2013, but in the last five years, new products have trickled out, and none have really introduced any new features or capabilities that their predecessors didn't carry as well. Many of the more recent POCs have been upgrades of existing models or products that were largely derived from the current product lines. If we expand our view to include other oxygen products like liquid oxygen systems and conserving regulators used on oxygen tanks, you realize there have been very few new products introduced after POCs entered the market. There clearly has been little push on the manufacturing side to release products capable of performing outside the established norms and expectations of home oxygen delivery systems.

*Above is an original Air Sep LifeStyle. We first wrote about it in our December 2001 issue. The battery lasted about 45 minutes for the pulse only machine and it weighed about ten pounds.*

There are some valid reasons for this lack of innovation that should not be discounted, primarily the changing economics in home oxygen reimbursement that have occurred over the last ten years. Liquid oxygen systems – still the lightest, longest-lasting option for portable use – have largely been phased out by home oxygen providers due to the cost of preparing, transporting, and delivering the liquid contents to their users. Oxygen users with high flow needs (greater than 3 LPM) have been particularly bitten by this change as the other options made available to them either are too cumbersome (numerous tanks and regulators) or simply can't meet

*Continued on page 12*

**Ryan Diesem is Research Manager at Valley Inspired Products, Apple Valley, MN. Contact Ryan at rdiesem@inspiredrc.com with questions or comments.**

*Continued from page 11*

their current oxygenation needs (POCs), especially when trying to be active. These are limitations that certainly can impact lower flow oxygen users on any type of system as well, but for many higher flow users, of what has been available, liquid oxygen was (and still is) an ideal system for portable use. With economics driving home oxygen decision making, any focus on providing products that come at a premium cost will certainly not be offered to the oxygen user since they will not be covered by insurances. Despite the clinical benefits new products could provide to oxygen users, the negative impact on the home care company's bottom line prevents these from becoming a reality.

Other factors as to why we haven't seen manufacturers innovate as much may include:

- **The rise of the POC.** Between 2002 and 2013, more than 25 models of POCs were introduced, the majority occurring after 2007. Manufacturers saw a hot commodity and jumped on the train, getting out a unit (or units) as quickly as they could. This meant focusing on making current technology work as quickly as possible, rather than exploring and/or expanding other ideas.
- **The limitations of oxygen separation technology.** All concentrators work by pulling in room air, removing the nitrogen gas, leaving the remaining oxygen to the user. This technology has been around for over 40 years now, but the methods behind the process have not changed much. In many ways you can look at oxygen separation technology as trying to squeeze as much juice as efficiently as possible from a lime – at some point, no matter how efficiently you do it, you just can't get any more juice from that lime, so you have to add more limes if you want more juice. In terms of POCs, this means having to add size and weight to the machine to accommodate the need for more materials to improve oxygen production. Manufacturers looking to develop higher flow POCs in a small enough design to be considered portable may have simply hit a technological dead end.
- **Lack of lung disease awareness and understanding.** Lung disease is the third leading cause of death in the United States, but it often does not get the public attention that other diseases receive – including from manufacturers, generous investors and supportive benefactors willing to promote advancements in lung disease treatments. Part of this may be due to a less-than-glamorous association with smoking that lung disease can carry, despite there being a multitude of other reasons – cystic fibrosis, alpha-1 antitrypsin deficiency, workplace contamination, etc. – that someone might have lung dysfunction and require oxygen or other drug therapies. Public attention means awareness, and awareness means a general population understanding the conditions, needs and benefits of lung-healthy treatments for those with lung disease. Without the attention and support of a larger community, development and innovation will happen at a slower pace and be limited by the resources currently available.

There is an obvious need for oxygen systems that are better than what is on the market today. With the current economics of home oxygen, availability of liquid systems is going to be limited, leaving old fashioned cylinders with regulators and POCs as the primary portable options for oxygen users. Since cylinders are large, bulky and not very efficient when it comes to storage capacity (meaning they run out quickly when used, especially smaller-sized cylinders), POCs will likely remain the main focus of manufacturers' oxygen product development going forward. That said, the SeQual Eclipse POC was introduced in 2005, when only a handful of POC options were available. The Eclipse was the POC with the highest production capacity – it has an output of 3 LPM continuous flow – and highest number of user features. It is now 2018, numerous POCs have since been made available, and that description from 2005 still largely applies. Further, in the 1980s, the late Dr. Thomas Petty (known as the "father of home oxygen") stated that the ideal portable oxygen concentrator was one that weighed less than 10 pounds, could deliver 2 LPM of continuous flow, and have a single battery or operating life away from home for a minimum of four hours. In 2018 there are only two devices that come close to that description, but neither of them can deliver 2 LPM continuous flow for four hours on a single battery charge.

There is still a need for an improved delivery system beyond what is currently available, especially for those with higher oxygen needs. If we can't have liquid oxygen systems as an option because no one will pay for and cover them, this system is going to have to

improve on currently available POCs so that more users can benefit from their use. Is a 5 LPM continuous flow capable concentrator with robust pulse delivery settings and sufficient battery life that much of a pipe dream? I don't think so. Would it be larger than ideal in size due to technological limitations? Probably. Would it have its own set of operating limitations? Definitely; every system does. Is it a difficult proposition to tackle? You bet. Would oxygen users be interested in a system like this? If the questions and feedback we regularly receive at *The Pulmonary Paper* are any indication, the answer is a resounding 'Yes!'. My hope is that in the 2019 or 2020 May/June issue of *The Pulmonary Paper* that we have such a device listed in our guide. Here's to hoping.

## Thumbs Up!

I recently came up with what I consider to be a brilliant idea! Some of the biggest problems that we encounter in the world of lung disease are awareness and the reluctance of people to be seen wearing their oxygen cannula. What if whenever someone sees a person wearing a cannula, they give the wearer a "thumbs up" gesture? This would acknowledge that you know they are doing what they should be doing to stay active. It would act as a sign of encouragement and hopefully take away some of the "shame and blame" nonsense oxygen users feel. Wearing oxygen protects hearts and brains by maintaining saturation, a very good reason to use it!

We all know that COPD is the third largest killer in the United States, after heart disease and cancer. We lose one of our community every four minutes. Yet, the funding for research for a cure for COPD is the under-appreciated stepchild of research funding. In 2012 the amount spent for research per person with AIDS was $2,787. During the same period, the amount spent for research per person with COPD was $4. That seems impossible, but those are the figures. So, why the difference? AIDS kills relatively few people these days, but the money keeps pouring in. Meanwhile, COPD effects some 30 million people in the United States but we are really hurting for research money.

Why would that be?

The advocates for AIDS research were highly visible. They were seen and they were loud! They held rallies and they marched in parades. The general public and the people who make laws could not help but notice. AIDS was considered to be a serious epidemic, and Congress and state legislators threw money at it. Celebrities of all kinds got behind the cause, and Tom Hanks starred in *Philadelphia,* a wonderful movie about a man with AIDS. The responses, the support, the noise were overwhelming.

***So, what are <u>we</u> doing?*** We are refusing to wear our cannulas where anyone can see us. We are staying home rather than exerting ourselves to gather our $O_2$ equipment and going out to live our lives. We are bearing the self-imposed shame and blame because we smoked years ago. We are sitting around feeling sorry for ourselves, instead of working the rest of our bodies to stay strong. We are doing everything we can to avoid drawing attention to ourselves.

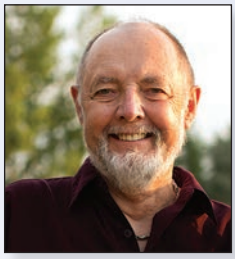
All of this helps to explain why I have taken up the "Thumbs Up" campaign. It

isn't parades and rallies and movies, but maybe the friendly gesture will be a start toward convincing people with COPD that being seen out in the world wearing a cannula is not nearly the worst thing in the world. I would like to ask for your help in promoting my idea, by talking to your family and others, and otherwise spreading the word. The "Thumbs Up" might just start a conversation. We could certainly use one!

The more people that we can get involved, the more effective it will be, and the fewer strange looks we will get. I would recommend accompanying the thumb with a genuine smile. Can't hurt. Thanks in advance for your help.

***Uncle Jim***

PS: Do not use the gesture in Iran, Afghanistan, West Africa, or parts of South America. It is considered highly offensive. The people of Greece won't use it but will tolerate it from foreigners.



*Jim Nelson, diagnosed with COPD, was lucky enough to have a lung transplant. He and his wife, Mary, are now advocates for those coping with respiratory problems. You may follow their advice at their blog, www.unclejim-auntmary.net*

## Thoughts

Well Spouse Association
Support for spousal caregivers

**The Well Spouse** Association advocates for and addresses the needs of individuals caring for a chronically ill person. Visit their web site at *www.wellspouse.org* or call 1-800-838-0879 to find a support group near you.

The organization was established in response to the book, *Mainstay: For the Well Spouse of the Chronically Ill*, by Maggie Smith. It is now out of print as it was originally printed in 1988 but available on Amazon. Some of the information is a bit dated but still great information for the well spouse!

---

**Donna B. from** Rochester, NY, wrote: Because I travel to my family's homes frequently, I need a truly portable nebulizer for my aerosol treatments. I have been pleased with the Aerosoon NebSmart Handheld which I have used in the car and I use it on planes. There is minimal noise from the nebulizer – no one even knows you are using it. It is very lightweight and has a rechargeable battery.

It is on Amazon.com for about $60. There are many other models available also. There is now no reason to stay home!

## Spring Cleaning: What's in Your Spray Bottles?

A February 2018 issue of *Newsweek* magazine discussed the impact of cleaning sprays and products on women's lungs being as damaging to those who regularly use them as a habit of smoking 20 cigarettes a day.

Scientists at Norway's University of Bergen tracked 6,000 people who regularly used cleaning products over a period of two decades, according to research published in *American Journal of Respiratory and Critical Care Medicine*.

The scientists advised avoiding cleaning products and instead use microfiber cloths and water. Some household chemicals contain chemicals called VOCs – volatile organic compounds. These chemicals evaporate into the air when we use them or even while they are being stored. Some examples of VOCs are acetone, benzene and formaldehyde. They may be found in detergents, furniture polish, air fresheners, carpet cleaners, oven cleaners, pesticides and fungicides, paints, paint strippers and varnishes.

Formaldehyde is a VOC that may be found in carpets, furniture, shelving and flooring. This can be why the smell of a new sofa or soft furnishing sets off your allergies or makes asthma worse.

Never mix bleach or any bleach-containing product with any cleaner containing ammonia. The gases created from this combination can be deadly!

Look for products that are labeled allergy friendly, as these have lower levels of volatile chemicals and are usually fragrance-free. Avoid sprays and opt for solid or liquid cleaning products. Try baking soda for scrubbing. A mix of vinegar and water can clean glass. Also be sure there is adequate ventilation when you clean.

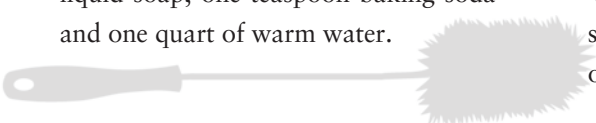
The American Lung Association tells us that manufacturers are not obligated by U.S. law to list all ingredients in consumer products. Products that are labeled "green" do not necessarily mean they are safer.

The U.S. Environmental Protection Agency has a list of products that meet its safer choice requirements for cleaning and other needs. They include cleaning products for home and vehicles. Visit *www.epa.gov/saferchoice/products*

## Tips for Spring Cleaning

The tradition of spring cleaning may have begun long ago when people used to spend the winter living in the same building as their animals, so a spring clean was needed when the weather turned nice and when the animals went outside. Different cultures clean their homes in anticipation of the new year (which occurs shortly after our new year) and to get rid of bad luck and misfortune that may have accumulated during the previous year. It could be we are exposed to more sunlight which gives us more energy. We hope you will find these cleaning tips for people with lung problems helpful!

- Start your task after you have taken your bronchodilators.
- Be realistic. Do one room or part of a room a day and pace yourself through the task.
- Gather all the cleaning products you'll need and put them in a pail or basket you will be able to carry with you.
- Use instruments and tools that make household cleaning easier and less strenuous – like lightweight vacuums and long-handled dusters. Make sure your vacuum has a filter on it so you don't inhale the dust. Use pursed lip breathing when doing the task!
- Have your windows open when you clean for ventilation.
- Avoid using strong scented cleaners. Use non-toxic natural cleaners such as baking soda and vinegar. For an all-purpose household cleaner, mix one teaspoon liquid soap, one teaspoon baking soda and one quart of warm water.
- If you spray water on the bottom of your broom when you sweep, the dust and animal hair will stick to it rather than filling the air for a chance to be inhaled. A damp cloth for dusting does the same thing.
- A mop is good for wiping down walls.
- Replacing carpeting with tile or wood floors makes it easier to keep clean. Blinds can also be dust collectors.
- Use a long-handled dust pan to avoid bending over after you sweep, as well as long handled sponges to clean the bathtub.
- Moisture breeds bacteria and mold. Make sure you do not have any water leaks in your shower or basement and replace your sponges and dish rags frequently. Every homeowner should own a hygrometer that measures temperature and relative humidity (RH). The ideal relative humidity for health and comfort is about 40 to 50 percent. In the winter months, it may have to be lower than 40 percent RH to avoid condensation on the windows.
- Many feel that wearing a mask avoids inhaling dust and particles while others feel the mask hinders their breathing. The choice is yours! You can get inexpensive disposable dust masks on the Internet for about two cents each.
- Have your air ducts cleaned professionally to avoid breathing in dust and dirt that accumulates in them.
- Do not let people smoke in your home. We display a sign that says. "If you are smoking in this house you had better be on fire!"



## Let's Celebrate Growing Older!

**To celebrate growing older, Regina Brett wrote down lessons life taught her. See how many you agree with and if you can add any to the list!**

1. Life isn't fair, but it's still good.
2. When in doubt, just take the next small step.
3. Life is too short to waste time hating anyone.
4. Your job won't take care of you when you are sick. Your friends and parents will. Stay in touch.
5. Pay off your credit cards every month.
6. You don't have to win every argument. Agree to disagree.
7. Cry with someone. It's more healing than crying alone.
8. It's OK to get angry with God. He can take it.
9. Save for retirement starting with your first paycheck.
10. When it comes to chocolate, resistance is futile.

11. Make peace with your past, so it won't screw up the present.
12. It's OK to let your children see you cry.
13. Don't compare your life to others. You have no idea what their journey is all about.
14. Care for your neighbors.
15. Take a deep breath. It calms the mind.
16. Get rid of anything that isn't useful, beautiful or joyful.
17. Whatever doesn't kill you really does make you stronger.

18. It's never too late to have a happy childhood. But the second one is up to you.
19. When it comes to going after what you love in life, don't take no for an answer.
20. Burn the candles, use the nice sheets, wear the fancy lingerie. Don't save it for a special occasion. Today is special.
21. Over prepare, then go with the flow.
22. The most important sex organ is the brain.

23. No one is in charge of your happiness but you.

24. Frame every so-called disaster with these words: *In five years, will this matter?*

25. Always choose life.

26. Forgive everyone everything.

27. What other people think of you is none of your business.

28. Time heals almost everything. Give time, time.

29. However good or bad a situation is, it will change.

30. Don't take yourself so seriously. No one else does.

31. Believe in miracles.

32. Don't audit life. Show up and make the most of it now.

35. Your children get only one childhood.

34. Growing old beats the alternative – dying young.

35. All that truly matters in the end is that you loved.


36. Get outside every day. Miracles are waiting everywhere.

37. If we all threw our problems in a pile and saw everyone else's, we'd grab ours back.

38. Envy is a waste of time. You already have all you need.

39. No matter how you feel, get up, dress up and show up.

40. Life isn't tied with a bow, but it's still a gift

Even though most people don't know it, lung cancer is the number one cancer killer of both women and men. It is the cause of one in four cancer deaths in the United States. Every two-and-a-half minutes someone will be diagnosed with lung cancer, with an estimated 234,030 new cases this year.

Recently, and for the first time, the American Lung Association (ALA) released a report called *LUNG FORCE: State of Lung Cancer*. It features statistics of each state to help our legislators ensure Americans may lead a smoke-free life, have access to early detection of lung cancer and care, with support a top priority. (The report may be viewed on the Internet at *Lung.org/solc)*.

ALA President Harold Wimmer notes, "The *State of Lung Cancer* report makes it clear that as a nation we need to do a better job. Every state needs to make prevention a priority with proven, effective policies and to also ensure screening facilities are available for those eligible for screening, regardless of where a person lives. This is how we'll save lives."

Lung cancer diagnoses and survival rates vary state by state. By better understanding the impact of lung cancer across the nation, efforts and policies can be focused where the needs are greatest. Each state was ranked on the following:

- **Incidence:** The rate of new cases varies greatly by state. The report finds that Utah has the nation's lowest lung cancer rates while Kentucky has the highest. There are a variety of risk factors associated with the disease, including smoking, exposure to radon gas, air pollution

and secondhand smoke. Radon testing and mitigation, healthy air protections, and reducing the smoking rate through tobacco tax increases, smoke-free air laws and access to comprehensive quit smoking services are all ways to help prevent new lung cancer cases.

- **Survival rate:** Unfortunately lung cancer is not often caught at an early stage when it is more likely to be curable. The five-year lung cancer survival rate ranges from 24 percent in New York to 15.9 percent in Louisiana.
- **Early or late diagnosis:** People diagnosed at an early stage of lung cancer are five times more likely to survive but only 18.9 percent of lung cancer cases are diagnosed at an early stage. The percent of cases diagnosed at an early stage – when it is most likely to be curable – was highest for Wyoming at 23.3 percent and lowest for Hawaii and Oregon at 15 percent.
- **Screening centers:** The ALA report finds that those living in states with greater availability of accredited lung cancer screening sites generally have greater early diagnosis and survival of lung cancer. Delaware had the most screening centers per million people at 21.1, while Utah had the fewest centers per million people at 0.7.
- **Surgical treatment:** Lung cancer is more likely to be curable if the tumor can be surgically removed, and surgery is more likely to be an option if the diagnosis is made at an early stage before the cancer has spread. Nationally, 21 percent of cases underwent surgery as part of the first course of treatment, ranging from 30.1 percent in Massachusetts to 14.3 percent in Oklahoma.

You may sign a petition at the ALA site to call on your state governor to make combating lung cancer a public health priority.

## Types of Lung Cancer

The American Cancer Society tells us there are three types of lung cancer. Non-small cell lung cancer is the most common type of lung cancers compromising about 85 percent of all lung cancers. Squamous cell carcinoma, adenocarcinoma, and large cell carcinoma are all subtypes of non-small cell lung cancer.

If you have non-small cell lung cancer, your doctor will want to find out how far it has spread to determine what type of treatment is best for you. This is called staging. The stage describes the spread of the cancer through the lung. Your stage can be stage 1, 2, 3 or 4. The lower the number, the less the cancer has spread. A higher number, such as stage 4, means a more serious cancer that has spread beyond the lungs.

The second type, small cell lung cancer, also called oat cell cancer, makes up about 10 to 15 percent of all lung cancer. It tends to spread quickly.

Lung carcinoid tumor or lung neuroendocrine tumor is the third type which makes up fewer than 5 percent of all lung cancers. Most of these grow slowly and rarely spread.

# Sharing the Health!

**Singing 4 Breathing** is a choir originally set up by occupational therapy students for people diagnosed with COPD in Wellingborough in the United Kingdom. What began as a short six-week project has turned into a successful group who sing at different venues in their area. You can see how beautiful they sound and the fun they have in their videos on *youtube.com*. Visit their Facebook page at *www.facebook.copdsingers*

**Another portable oxygen** concentrator called the Mobi is about to enter the market. The manufacturer is ResMed, known for its sleep apnea equipment. They purchased the Activox 4L in 2016 and the Mobi is thought to be an upgrade to this POC. Stay tuned for updates!

**Temple University in** Philadelphia had the busiest lung transplant program in the United States in 2017 with 131 lung transplants, up from 101 in 2016. Of those transplants, 54 percent were 65 years old or older compared to the national average of 33 percent. For information visit *https://lung.templehealth.org* and click on Patient Care and Centers & Programs or call 1-800-836-7536.

**Could someone please** make oxygen tubing that will blend in more and certainly not in green? If we had cannulas that were made of various skin colors, they wouldn't stick out so much! My supplier finally gave me ones that were at least clear. My granddaughter used her paints to mix up a flesh color and painted one of my cannulas; I didn't want to risk breathing in any paint flakes but really like the idea!

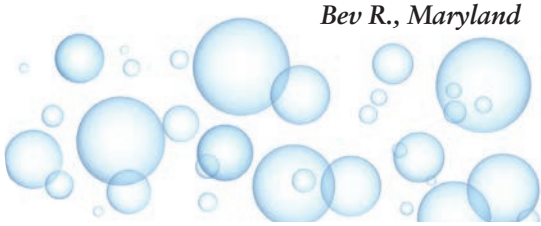
***J.M., Minnesota***

**Therapist Dr. Ed** says at the age of 76, he has recovered many times: asthma (age 7), alcoholism (age 40), obesity (age 45), smoking (age 60), broken back (age 63), cancer (age 65), broken knee (age 70), and now COPD.

His web site *www.recoverythinking.com* offers a workbook to help you work through your feelings about having lung disease. We thank him for sharing his experience with us!

**Now that spring** is coming, I enjoy going to the park and blowing bubbles! Purse your lips and slowly blow bubbles for the pure enjoyment of it and you just might put a smile on someone's face besides your own!

***Bev R., Maryland***




**Spring Quiz:** We thought we would keep the quiz light and ask you to answer these questions that contain the words March, April or May. Enjoy!

1. Jazz standard originally performed by Freddy Martin but made most famous by Count Basie.
2. Irene Hunt novel about the American Civil War, often considered the first Young Adult novel.
3. Common distress signal to denote a life-threatening emergency.
4. Poet and novelist, writer of 'Phenomenal Woman' and 'I Know Why the Caged Bird Sings'.
5. Character from the tea party scene in 'Alice in Wonderland'
6. News reporter and friend to the Teenage Mutant Ninja Turtles
7. Song from 'Sounds of Silence' by Simon and Garfunkel.
8. Nickname for either John Philip Sousa or Kenneth J. Alford.
9. Date noted in history for the assassination of Julius Caesar.
10. Dave Matthews Band song from 'Under the Table and Dreaming'.
11. Cold War-era Burt Lancaster and Kirk Douglas movie about a planned military coup against the President.
12. Richard Matheson novel or its adaptation starring Robin Williams about the afterlife.
13. Aquatic insect, closely related to the dragonfly.
14. Creators of the only known writing system in pre-Columbian America.
15. Song by Sublime from their self-titled album about the Rodney King riots.
16. Ship that famously transported the Pilgrims to the New World.
17. Holiday noted for practical jokes and hoaxes.
18. The protagonist of 'Little Women'.
19. Common name for the NCAA Men's Division I Basketball Championship.
20. Foundation formerly referred to as the National Foundation for Infantile Paralysis.

## Answers to Last Issue's Heart Quiz

**1.** There are two systems in which blood travels in the cardiovascular system. What are they?
**Pulmonary and Systemic:** The pulmonary system starts with dexoygenated blood coming out of the right ventricle. It is pumped up through the pulmonary artery and circulates around your lungs where it is oxygenated by the air you breathe in. Blood then returns to your left atrium to be pumped to the rest of your body in the systemic system.

**2.** Blood flows through the heart in this order: right atrium, right ventricle, pulmonary circuit, left atrium, left ventricle … into what vessel is the blood pumped from the left ventricle?
The **aorta** extends down into the abdomen where it splits into two smaller arteries to deliver oxygenated blood to all parts of the body.

**3.** In a blood pressure measurement reading 120/80, the number on the bottom is which reading?
The **diastolic reading**, or the bottom number, is the pressure in the arteries when the heart rests between beats to fill with blood. (The systolic, or top number, is when your heart beats to push blood through your arteries.)

**4.** Which chamber receives the deoxygenated blood from the systemic system first?
The **right atrium** receives blood first.

**5.** What is the medical term for a severe constricting pain in the chest due to an insufficient blood supply to the heart?
**Angina pectoris** is pain due to coronary artery disease which usually happens because one or more of the heart's arteries is narrowed or blocked.

**6.** What drug would you use for relief of the constricting chest pain?
**Nitroglycerin** dilates or widens blood vessels, making it easier for blood to flow through them and easier for the heart to pump.

**7.** A small mass of specialized muscle on the back wall of the right atrium, also known as the pacemaker, is medically known as what?
The **sinoatrial node** or **sinus node** sends electrical impulses further down to the atrioventricular node to cause the heart to contract.

**8.** When you check the pulse of someone by placing two fingers on the side of their neck, you are feeling the blood being pumped through which vessel(s)?
**Carotid artery**. There are eight main pulse points in the human body. These additional pulse points are located in the wrists, at the sides of the lower jaw, at the temples, on the inner biceps, behind the knee, in the groin and on the upper part of the foot.

**9.** The system of arteries that supply the heart with its own separate supply of blood is called coronary arteries.
The four primary coronary arteries are located on the surface of the heart: **right main coronary artery, left main coronary artery, circumflex artery and left anterior descending artery**.

**10.** What is meant by the term hypertension?
**High Blood Pressure**. Hypertension, known as the silent killer because many do not realize they have it, is characterized by a consistent high pressure when the blood pushes through the blood vessels.

**11.** Which is *not* a result of hypertension?
**Headache**. Chronic hypertension also may cause stroke, dementia, eye damage, sexual dysfunction, bone loss and trouble sleeping.

**12.** What is the correct medical terminology for a heart attack?
**Myocardial infarction**. A heart attack occurs when blood flow decreases or stops to a part of the heart, causing damage to the heart muscle.

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Reference:
1. Svenningsen S, *et al.* COPD 2016;13(1):66–74.

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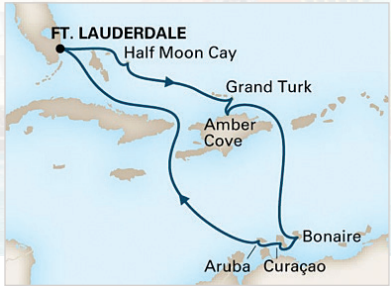


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- **Bar Harbor, Maine**
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- **Halifax and Sydney (Nova Scotia)**
- **Charlottetown (Prince Edward Island)**
- **Quebec City**
- **Montreal (Quebec)**

# Respiratory News

**Existing research suggests t**hat approximately 45 percent of all people with COPD report chronic pain as moderate to severe and located primarily in the chest, shoulders, neck and upper arms. Pain in and of itself is not a symptom, but often musculoskeletal in nature and commonly associated with the work of breathing. A recent study in the *International Journal of Chronic Obstructive Pulmonary Disease* determined those with COPD need comprehensive pain management and should discuss this with their physician.

***The Journal of** the COPD Foundation* found that study participants with severe COPD have poor dental hygiene practices, and a diminished oral health-related quality of life. In the setting of poor dental health, the greater number of teeth that a participant had correlated with worsened daily respiratory symptoms such as cough and wheeze. These findings support the idea of potentially targeting oral health to improve COPD outcomes in future trials.

**A new warning** about vaping published in *Environmental Health Perspectives* says there may be toxic levels of metals, including lead, that could be leaking from the heating coils of e-cigarettes. Researchers from Johns Hopkins School of Public Health found metal traces in the aerosols inhaled by users (known as "vapers"). The FDA has the authority to regulate e-cigarettes, but has not issued any rulings on the matter so far.

**Johns Hopkins investigators** say they now understand the underlying biology behind pulmonary hypertension. Working with cells that line the innermost layer of the blood vessels, they discovered that a protein called KLF15 protects these cells from damage during low blood oxygen levels. KLF15 is also likely a key regulator of genes important for maintaining proper function of lung blood vessels. Investigators say they were able to genetically alter cells grown in a dish in a way to increase KLF15 and reverse the damage – restoring the cells to normal function despite exposure to low oxygen levels. The research appeared in the journal *Arteriosclerosis, Thrombosis and Vascular Biology*.

**Regular aspirin use** was associated with a more than 50 percent reduction in COPD progression according to analysis of data from a large lung study published in the journal *CHEST*. The association was seen across aspirin doses and was greatest in older study participants with significant airflow obstruction.

***H. influenzae* is** the leading bacterial cause of exacerbations of COPD. Identifying genetic variations within its DNA is critical for developing new methods to treat and prevent this disease. Research published in the *Proceedings of the National Academy of Sciences* sheds new light on how the bacterium adapts quickly and may help identify new therapies for those with COPD. *H. influenzae* also causes ear infections and pneumonia.

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**Associate Editor**
Dominic Coppolo, RRT, AE-C, FAARC
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**Medical Director** . . . . . Michael Bauer, MD

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