

The Pulmonary Paper

Dedicated to Respiratory Health Care

January/February 2019 Vol. 30, No. 1

YOU NEED TO
LOVE AND ACCEPT YOURSELF

to Truly Enjoy Your Life!



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Plan an adventure with the Sea Puffers Family!



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

St. Valentine Quiz

1. St. Valentine is indeed the patron saint of love, but he has many other duties. He is also the patron saint of:
 - a. Actors
 - b. Bee keepers
 - c. Orphans
 - d. Vinegar makers
2. We associate love with the heart, but in Shakespeare's time it was not always so. In what other organ did love reside?
 - a. Kidneys
 - b. Liver
 - c. Pancreas
 - d. Spleen
3. It's the eighteenth century, and your sailor sweetheart has just given you what is called a "busk valentine". What is it?
 - a. A kiss
 - b. A piece of decorated whale-bone
 - c. A song in which the singer vows fidelity
 - d. A trinket from a far-off place
4. Thanks to the efforts of certain businesses, Valentine's Day has been popular in Japan since the 1950s. It is now customarily celebrated by:
 - a. Exchanging body grooming products and scents
 - b. Extravagant meals at special "love diners"
 - c. Men giving electronic products to women
 - d. Women giving chocolate to men
5. The custom of wearing a wedding band on the fourth finger of the left hand can be traced back to this ancient kingdom, where it was believed that the vein of love coursed through this finger directly to the heart.
 - a. Egypt
 - b. Babylonia
 - c. Sumeria





Editor's Note

You may feel guilty for having smoked. You may think you need to lose weight or wish you had more money. There are many things we wish we could change about ourselves thinking it would make our lives better.

If you can learn to live without expectations of others, you will take a lot of pressure off yourself. You can choose to hold a grudge or make peace. Accept the changes and losses in your life. Accept limitations and learn to love things and yourself the way they are. If you have no expectations, there can be no disappointments. We are not saying you should stop trying to be the best you can be, just don't ever feel you are not good enough!

We all have made mistakes, forgive yourself. Try increasing your self-esteem by keeping a journal or meditation, and you will have a very positive 2019!

Carole

“Owning our story and loving ourselves through that process is the bravest thing that we’ll ever do.”

— Brene Brown,
author



Love and Lung Disease

Just in case you always wanted to know but were afraid to ask, we found articles for you on sexuality and lung disease!

Maintaining Your Sex Life with COPD,
www.verywellhealth.com/sex-and-copd-914978
<https://tinyurl.com/ydet83hd>

Sex and Breathlessness, www.blf.org.uk/support-for-you/sex-and-breathlessness

How COPD Affects Your Sex Life, www.healthline.com/health/copd/sex#1





Dr. Michael Bauer

Calling Dr. Bauer ...

As we start the New Year, I would like to offer my Pulmonary Paper readers my top ten bits of advice for those living with lung disease.

- 1 Write down the names of all your medications and inhalers. Keep a copy in your wallet, purse and on your refrigerator.
- 2 Know the proper technique for using all your inhalers. If/when you see your lung doctor, have him/her or the respiratory therapists in the office review the proper technique for each inhaler you use. Inhalers don't work unless you are using them correctly!
- 3 Those with severe lung disease should have frequent small meals during the day, rather than regular "three big meals".
- 4 Keep your durable medical equipment (oxygen concentrator, portable tanks, CPAP machines, tubing, masks) clean and in good working shape. Have your home care provider check them out on a regular basis.



- 5 Get your annual flu shot and be up to date on your pneumonia and shingles vaccines.
- 6 Exercise every day. For some, that means more walking inside every day. For those that can, take a walk outside or at a local mall. Fresh air is good.
- 7 Ask your doctor if there is a formal Pulmonary Rehab Program in your area. Almost all my patients say that rehab is one of the best things they have ever done to improve their breathing and exercise abilities.

- 8 Try your best to stop or cut back on a smoking habit. Encourage the same for family members and friends that may smoke. Ask for help if you need it.
- 9 Pick a new goal for 2019. It can be anything you want. Maybe something related to your health. Maybe a new hobby. A new travel adventure. Making a new friend. You are limited only by your imagination.

- 10 As a physician, I can see how hard it is for many of my friends and patients to live day to day with their lung disease. It limits all of you in many ways. Trying your best to have a smile, appreciating your family and friends and thanking them for supporting you will be paid back many more times with their love and support.

Questions for Dr. Bauer?
You may write to him at
The Pulmonary Paper,
PO Box 4275, Ormond
Beach, FL 32175-4275
or by email at info@pulmonarypaper.org.

Do you OR does someone you know live with COPD and Sleep Apnea?

The COPD Foundation and American Sleep Apnea Association have partnered to develop a patient-centered study that will provide participants with peer support, a virtual classroom and feedback on how they are using their CPAP device through remote monitoring.

The study intends to provide participants with information and peer support that supplements their medical care and in no way replaces the guidance of their physician or other healthcare providers.

The study hopes to improve CPAP use and therefore improve quality of life.

- Study activities are all done via telephone and on-line communications.
- Participation lasts about 90 days.
- Participants may be compensated up to \$75.00 for their time.

Study eligibility criteria:

- 40 years or older
- Diagnosed with COPD and Sleep Apnea
- Prescribed a CPAP device
- CPAP device has a wireless modem

visit **www.O2VERLAP.org** to learn more

For more information:

Please call the study coordinator at
1-866-731-2673 ext. 210 or email at
O2VERLAP@copdfoundation.org

Thank you!



O₂VERLAP Study



**Mark Mangus, RRT
EFFORTS Board**

A comprehensive exercise and conditioning program coupled with increasingly demanding physical activity in daily life are essential to improving your health and well-being, your symptoms and quality of life with COPD.

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.

Ask Mark ...

An Arkansas EFFORTS member tells Mark she is walking 10 minutes daily and asks why exercise is so important for lung disease?

Mark replies, Folks with COPD and other chronic lung diseases can become trapped in what we call “the vicious or downward spiral”: You have trouble breathing when you move about. So you avoid it. The more you sit, the more out of shape you become so the more you sit. At some point, you find you cannot get up and move about without significant and perhaps immediate breathing difficulties. You will become more susceptible to exacerbations and infections.

The only way to survive and thrive with chronic lung disease – especially with COPD – is to “move it or lose it”! That’s why it is so important to exercise – exercise every part of your body – not just walking!

Learn breathing techniques like pursed lip breathing. Don’t stop your exercise to recover from your breathlessness. The more you stop to recover, the less you become “desensitized” to the hard breathing and the less your condition improves to reduce that hard breathing!

For folks who are extremely deconditioned, I have them walk on a level treadmill to build up tolerance, speed and duration before adding grade. I suggest you should try this until you can walk 20 to 30 minutes without stopping, building up the speed to 2 mph if you can. Adding “interval” training will effectively build strength and conditioning. Example: Walk at 1.2 mph for 5 minutes. Then up the speed to 2 mph and walk for a few minutes – until you get winded and are breathing harder than at the 1.2 mph. Drop your speed back down to 1.2 mph and keep walking. Don’t stop! When you stop to catch your breath and let your breathing settle down, you lose your head of steam. Push yourself to continue!

If you can, walk on the flat treadmill for a significant time, alternating both the speed and grade. Don’t do the same exercise pattern day in and day out. That is a monotonous exercising pattern that your muscles get use to. You then gain less conditioning from your effort.

A broad, comprehensive exercise program includes strength training using resistance exercises, like lifting weights for building arm and chest muscle strength. Weights can be a bag of dried peas/beans which come in 1, 2 pounds, etc. Simple leg exercises, like doing sit-to-stand repetitions without using your arms to help you stand, build strength in your legs and derriere muscles. Standing for increasing periods of time and doing various Tai Chi poses and movements to improve strength and balance are essential. Yoga for breath control and relaxation is very helpful.

Fibrosis File

Top Pulmonary Fibrosis stories of 2018 from *Pulmonary Fibrosis News* include:

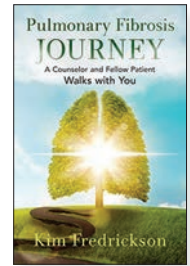
- The CDC reported that dentists and other dental health care personnel may be at risk of developing idiopathic pulmonary fibrosis (IPF).
- Esbriet and Ofev show significant benefits in slowing IPF progression.
- A 12-week treatment with experimental drug PBI-4050 stabilized lung function both as a stand-alone therapy and in combination with Ofev. Phase 3 clinical trials will be conducted.
- Another investigational treatment pam-revlumab halted the progression of lung scarring and improved the lung function of people with IPF over a 48-week period. It is now on the FDA's Fast Track which speeds up the approval process.
- A common diabetes medication, metformin, was found to lessen the effects of pulmonary fibrosis.
- Sulphoraphane – a compound found in broccoli, cauliflower, Brussels sprouts, kale, cabbage and bok choy – showed anti-fibrotic properties in pre-clinical experiments in cells and in a mouse model.

Physicians from all over the world collaborated on newly released guidelines for the diagnosis of IPF. The very technical information was published in the *American Journal of Respiratory and Critical Care Medicine*.



PF Warriors is a group inspirational to all! All are volunteers of people with Pulmonary Fibrosis, families and medical professionals helping each other in living with PF. They hold scheduled meetings featuring presentations, information, discussions and fellowship for PF people and families where you can attend in person or virtually. Visit them on the internet at <https://pfwarrior.com> and join at no cost.

Counselor Kim Fredrickson has pulmonary fibrosis. She has written *Pulmonary Fibrosis Journey: A Counselor and Fellow Patient Walks with You*,



available at *Amazon.com* for \$14.99. She discusses many topics including:

- Know what to do when first diagnosed;
- Learn ways to work through emotional turmoil and grief;
- Develop a support system and tools for self-care;
- Give caregivers the information and support they need;
- Find ways to stay as healthy as possible for as long as possible;
- Learn the ins and outs of using supplemental oxygen;
- Understand the stages of pulmonary fibrosis;
- Get information on treatment options;
- Obtain palliative care and address end-of-life issues;
- Address spiritual concerns.



Ryan Diesem

The Ryan Report

Home Oxygen Guru – The HO₂G Pen

Question & Answer

Do you know if you can use oxygen in the swimming pool? I know you can use a concentrator if it is 10 feet away in the shower, but I have never heard anything about using one for swimming. Would you please advise?
R.G.

Ryan answers, This is a good question that I wish would get asked more often, as I think many folks assume that it is not possible or just inconvenient to use oxygen while swimming or in and around water.

One question I think most people would have is ‘Doesn’t water get in the cannula?’ and the answer to that is, if the person is using continuous flow oxygen from a high-pressure source (this includes your concentrators, regulator/tank systems, and LOX, pretty much any device that outputs

continuous flow), it is OK to wear your cannula and receive oxygen while in the pool, lake, or river. If you want to demonstrate that you can go in and around water with your cannula on, just submerge the cannula with flow running and observe the bubbles. Those bubbles are gas being pushed out of the cannula, and so water certainly is not going in. But also note that any water in or around the nose may be sprayed when surfacing, which could be uncomfortable.

Of course, appropriate precautions have to be taken with the equipment such as keeping all electrically powered equipment away from the water (long lengths of extension tubing solve this) or placing the cylinder/regulator or pneumatic LOX system (i.e., Helios, *not* the Spirit which uses batteries) in its own protected bucket/tube to float nearby. When this is

done, oxygen users should find it relatively easy to keep their oxygen on while in the water.

I will stress that pulse devices should not be used. With the intermittent flow that occurs, the cannula tubing is not consistently pressurized like in continuous flow so there is great likelihood that water does get into the cannula and impedes flow when the device is waiting for the next breath. Plus, there is the risk of the device triggering with water in the tube and spraying the user in the nose. Using a pulse device to deliver oxygen while you are in the water can be done if you really want to, but I can’t personally recommend it.



My friend Marty floats on a tube with his daughter, with his oxygen system in his lap.

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

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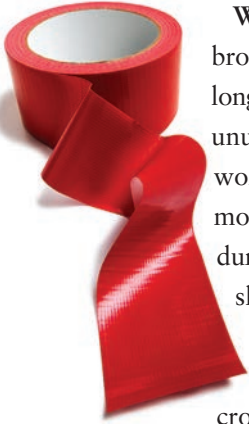
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Sharing the Health!

Peg Studdard puts her oxygen tubing in a mesh bag with a towel for 10 minutes in the dryer to warm it up. When she takes it out and stretches it out, it lays flat and eliminates the kinks in the tubing that would shut off her oxygen supply.



Margaret H. recommends no matter how you feel, make your bed in the morning. She recently heard this advice and thinks it works. It will make you feel like you accomplished something and give you a small sense of pride to start the day. This encourages you to complete other small tasks and at the end of the day, you will feel good about yourself!



When using a mop, broom, vacuum cleaner, or long handle duster, it is not unusual for us to continue working just a few more moments beyond our endurance and develop acute shortness of breath.

Create a large loop with Zip ties, or Velcro® straps, even cannula tubing. Attach it to the handle with extra strong duct tape if the tool does not already have an opening. Some mops already have a small loop to hang it to dry or a vacuum cleaner handle has a large opening. You want a loop large enough to easily place over a door handle.

The idea is to use this loop to quickly place it over the nearest door handle or knob before you sit to get control of your breath with pursed lip breathing. Once you are breathing well enough to continue your task, the tool will be at an easy height rather than having to bend over to retrieve it from the floor.

D. Penndorf, West Hartford, CT

Janis Shive from Edgewater, Florida, writes: As you can see from these before and after pictures, life is what you make it!



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Reference:

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

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The tax-filing season began on January 28, even amid the government shutdown. This is the first tax year under the Tax Cuts and Jobs Act – an overhaul of the code that doubled the standard deduction (\$12,000 for singles and \$24,000 for married-filing-jointly), and eliminated personal and dependent exemptions. The law also placed limits on itemized deductions. It is expected that only 10 percent of Americans will itemize deductions.

In the 2018 tax year, you are able to claim an itemized deduction for out-of-pocket health care costs that exceed 7.5 percent of your adjusted gross income.



If your total expenses were close to being over the standard deduction amounts, you could claim the electricity costs to operate your medical equipment. The IRS allows you to deduct preventative care, treatment, surgeries and dental and vision care as qualifying medical expenses. You can also deduct visits to psychologists and psychiatrists. Prescription medications and appliances such as glasses, contacts, false teeth and hearing aids are also deductible. The IRS also lets you deduct the expenses that you pay to travel for medical care, such as mileage on your car, bus fare and parking fees.

Answers to our Insurance Quiz in the November/December newsletter:

1. Which government program helps elderly Americans pay their health care costs? *Medicare is the health insurance program that helps seniors pay for health care. Medicaid is the program for those with low incomes.*
2. In health insurance, “network” means what? *A network is a group of doctors, hospitals and other health care providers contracted for services to insurance companies for less than their usual fees.*
3. Which of the following is a form of an out-of-pocket expense? *A copay is a fixed amount, often \$15 or \$20, that you pay for covered services like a prescription or a doctor’s visit and the insurance pays the rest.*
4. Which is not an example of a pre-existing condition? *A broken leg – a preexisting condition is any major medical problem as cancer, diabetes or asthma that is excluded from coverage because the person had that condition before purchasing their health insurance.*
5. Which is the major difference between an indemnity care plan and a managed care plan? *In indemnity, or “fee-for-service” health plans, the customer pays a percentage of their health care costs, while the insurance companies pick up the rest. Because of this, patients are free to choose their health care professionals and don’t have to participate in a network of doctors.*
6. What’s the main benefit of a managed care plan? *Managed care plans, a type of health insurance, provide you with lower health care costs because these services are part of a network of doctors, hospitals and other providers.*
7. What is a formulary? *It is a list of drugs an insurance company will not pay for. Often, an insurance company wants you to buy a less expensive generic drug.*
8. What does “HMO” mean? *Health Management Organization, it provides a fixed fee for services instead of charging for each visit or procedure.*
9. Which of the following statements best describes “reasonable and customary”? *This is the average fees paid in a specific geographic area. If your fee is higher, you may have to pay the difference.*
10. Which word/term best describes the amount you pay each year before your health plan begins paying? *A deductible - most plans have deductibles, which start over every January.*

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HIGHLIGHTS: Mallorca, Marseille, Antibes, Monte Carlo, Cinque Terre, Florence/Pisa/Tuscany and ending in Rome, the Eternal City



Respiratory News

People with COPD-related anxiety would benefit from cognitive behavioral therapy, a new trial in *ERJ Open Research* finds. The respiratory symptoms are often upsetting and many experience anxiety as well. This anxiety can aggravate a person's health, potentially resulting in repeated visits to the hospital. Cognitive therapy is a type of psychotherapy in which negative patterns of thought about the self and the world are challenged in order to alter unwanted behavior patterns.

A new study in *Thorax*, suggests a daily dose of Vitamin D may ward off lung infections for those with COPD. Researchers showed giving supplements to Vitamin D-deficient people with COPD nearly halves their rate of potentially fatal attacks. The investigators found there was no reduction among those with higher Vitamin D levels.

In early January 2019, the CDC reported there were more than 7 million people who had gotten the flu. Besides washing your hands frequently and avoiding those who are sick, think about cleaning your cell phone. Clean it thoroughly with a 90 percent alcohol cleaning wipe. Viruses not only travel from person to person contact, but viruses that may cause the flu can survive on hard surfaces like those of cell phones and keyboards for up to 48 hours. Avoid sharing personal devices with others!

An article on *www.medicalnewstoday.com* recently described pulmonary function. Read it at <https://tinyurl.com/lycupcyf2>

Inogen plans to unveil its latest Portable Oxygen Concentrator – the G5 – in the first half of this year. We can only hope the unit will have a high oxygen output with continuous flow!

An article in *CHEST*, reports among people with COPD, daily aspirin use is associated with fewer moderate acute exacerbations of COPD, especially among those with chronic bronchitis.

Global healthcare company, BTG, announced the start of ELEVATE: A randomized Controlled Study of PneumRx™ Endobronchial Coil System to treat people with emphysema. Recruitment will begin in European countries.

RT Magazine's Top Stories of 2018

American Thoracic Society physicians believe home oxygen services have worsened since the onset of the Competitive Bidding Program that began almost ten years ago and is now an urgent problem.

FDA approved Teva's ProAir Digihaler for asthma and COPD. It is the first inhaler with built-in monitoring sensors.

The European Commission recently approved AstraZeneca's Bevespi Aeroshere in the European Union for treatment of COPD using a pressurized metered-dose inhaler.



PH Top Stories of 2018

Among the top stories of 2018 reported by *Pulmonary Hypertension News* are:

- A compound known as osthole that is used in traditional Chinese medicine shows promise to lower lung blood pressure in those with Pulmonary Arterial Hypertension (PAH).
- People with PAH who can walk more than 437 yards in a 6-minute walk test were found to have a lower risk of hospitalization and better long-term prognosis. Those with little daily physical activity had lower survival rates.
- A study found that half of people with idiopathic or heritable PAH have some

degree of reduced levels of oxygen in their blood, either at rest or during physical activities. Reduced levels of oxygen in the blood were found to be associated with worse long-term survival, which could be alleviated with using supplementary oxygen.

- Researchers are planning to launch a clinical trial in 2019 to evaluate a new therapy, known as C76, that may inhibit and possibly reverse the damage to blood vessels in PAH.
- The FDA approved the first generic formulation of Adcirca (tadalafil) for improving exercise capacity in people with PAH.

The Pulmonary Paper

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