The Pulmonary Paper

July/August 2009

Dedicated to Respiratory Health Care

www.pulmonarypaper.org • Volume 20, Number 4

Northern Expo$_2$sure!

Also inside:

Calling Dr. Bauer

Legislative Updates

Sharing the Health

The Pulmonary Paper

News Magazine
Volume 20, No. 4
July/August 2009

On the cover: Chris, Ceil and Suzanne are all smiles on their adventure to Glacier Bay!

The Pulmonary Paper
PO Box 877
Ormond Beach, FL 32175
Phone: 800-950-3698
Email: info@pulmonarypaper.org

The Pulmonary Paper is a 501(c)(3) not-for-profit corporation supported by individual gifts.Your donation is tax deductible to the extent allowed by law.

contents

The hospital I work at, recently closed down and relocated patients to their new facility. The move was indeed an adventure! Good work, RTs!

> **"Only those who will risk going too far can possibly find out how far one can go."**
>
> **— T.S. Eliot**

***The Pulmonary Paper* Staff**

Editor
Celeste Belyea, RN, RRT, AE-C

Associate Editor
Dominic Coppolo, RRT, AE-C

Medical Director
Michael Bauer, MD

The Pulmonary Paper is a membership publication. It is published six times a year for those with breathing problems and health professionals. The editor encourages readers to submit information about programs, equipment, tips, or services.

Phone: 800-950-3698
Fax: 386-673-7501
www.pulmonarypaper.org

Will you have something to say when your friends ask, "Do anything interesting lately?" According to the *Encarta Dictionary,* an adventure is defined as an exciting experience: an extraordinary event or series of events, or a bold undertaking involving uncertainty and risk. Where's *your* sense of adventure? Are you willing to exercise a little longer or go faster than you ever have? Take a class or learn something new or go somewhere you have never been before? Every day we wake up can lead to an adventure – big or small. You just have to believe you can do it!

Celeste

Legislative Issues Update

If you would like to contact your elected representatives about issues that affect your living with lung disease, you may call the Capitol in Washington, DC, at 1-202-224-3121. The switchboard operator will connect you to your legislator's office by using your zip code. If you have access to the Internet, please visit www.house.gov to find out the name and number of your elected officials.

Operation 435, named for the 435 congressional districts, hopes to get $1 million in federal funding to invest in a national COPD action plan in the Centers for Disease Control's Chronic Disease Division. According to the COPD Foundation, "The federal government has campaigns to address and eliminate many diseases: diabetes, heart disease, stroke, kidney disease and more. COPD is the fourth leading cause of death in the United States, but there is no national coordinated effort to promote early diagnosis, prevention, treatment and management." For more information, visit www.operation435.com. To help this become a reality, become a squeaky wheel and let your member of Congress know how you feel. We just may get some grease!

The COPD Foundation has also partnered with WebMD to develop a Lung Health Check. After completing a questionnaire, you will receive three customized reports that offer resources to help cope with your respiratory problems and encourage you to be active in the process. To participate, visit www.webmd.com/lung-disease-health-check.

Two groups involved in supplying your home oxygen are expected to present "simplified" oxygen reform plans to the House of Representatives and the Senate this summer. The plans would eliminate the 36-month cap on Medicare reimbursement for oxygen, reclassify suppliers as providers and link reimbursement to patient needs. Oxygen will be recognized as a drug regulated by the FDA and therapy would be modality-neutral, allowing appropriate payments for new technology such as home transfilling equipment. Both groups seek to have their plans included in health care reform legislation. Currently, Bill H.R. 2373: Home Oxygen Patient Protection Act of 2009 was introduced by Representative Tom Price and has 74 co-sponsors.

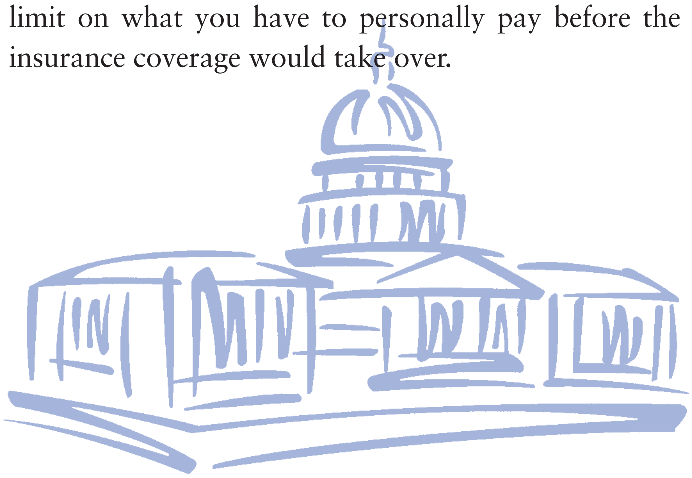
Pulmonary Rehabilitation Coverage

The Centers for Medicare & Medicaid Services (CMS) have posted new proposed rules for cardiac and pulmonary rehabilitation. CMS will accept comments on the proposed rules until August 31, 2009. Unless otherwise specified, the new payment rates and policies will apply to services furnished to Medicare beneficiaries on or after January 1, 2010.

CMS would cover Pulmonary Rehabilitation (PR) only for COPD patients with moderate to severe disease. *(Does this make sense to let the disease progress before teaching people how to cope with it?)* Every PR session must include some exercise, a limit of one session per day, which must be a minimum of 60 minutes, with a **maximum** of 36 sessions. Groups such as the American Association for Cardiovascular and Pulmonary Rehabilitation feel the proposed payment schedule is seriously flawed and grossly underestimates the cost of providing integral components of PR. If you have been helped by a PR program, offer your comments and opinions by visiting www.regulations.gov and search by file code CMS-1413-P. The docket title is Medicare Program, Payment Policies under the Physician Fee Schedule and Other Revisions to Part B for CY 2010.

Insurance Changes

Changes may be happening with your supplemental insurance coverage. Open enrollment begins on November 15 of this year. After Medicare payments are made, there are a wide variety of plans that want your business. They offer varying degrees of benefits so you need to review what the plan covers and how much it will cost you. If they offer low premiums, you need to find out if there is an out-of-pocket maximum. If there is not, there is no limit on what you have to personally pay before the insurance coverage would take over.



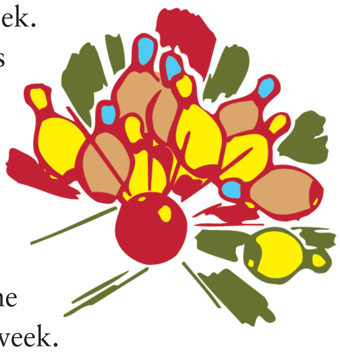
Non-adherence

We recently attended a lecture by Patrick Dunne, MEd, RRT, who talked about why people with chronic lung problems do not adhere to the treatment regime their physician has prescribed for them with controller medications. These are medications like Advair, Spiriva, Flovent, etc., that prevent acute attacks from happening in the first place. When you are dealing with an infection and increased shortness of breath, there is a sense of urgency to take medication to make you feel better. When you start to recover, the medication may not seem so necessary.

Patrick found the most common reasons for intentionally not taking medications were concerns about adverse effects; the drugs are too expensive; you feel you are not really that sick; you do not want to become "addicted" to them or they no longer seem to work. It is very important that you realize that people who do not take their inhaled controller medications are directly responsible for increased morbidity, mortality and health care costs. If you have questions about the medication that has been prescribed for you, please discuss them with your physician. It will be a lot easier for you to accept and stick with the plan if you understand what your doctor hopes to accomplish with your prescriptions.

Exercise: Mix It Up!

How much should you exercise? *The Journal of the American Association of CardioPulmonary Rehabilitation* recently summarized their recommendations. Those involved in pulmonary rehab should start out doing 30 to 90 minutes of low aerobic activity, 3 to 5 days a week. Work up to more strenuous exercise that puts you near 80% of your capacity. You should also do resistive exercise using hand or ankle weights, free weights, elastic bands and/or machine weights, 2 to 3 times per week.



People with COPD Are Expecting More!

RethinkCOPD is a new campaign by AstraZeneca, makers of Symbicort, that is aimed at getting people with COPD to consider their options with respect to diet, exercise and medication. The promotion features a celebrity, actor Robert Klein, who has been diagnosed with the disorder. Visit www.RethinkCOPD.com to find information on how to better understand your treatment choices. As Mark Mangus points out, "Once you learn a lot about your disease, you will likely become more comfortable with those things that now frighten you. Keep digging and learning and you'll be surprised how much better you feel, physically and psychologically, when you learn what fears are well-founded (few) and what fears are unfounded (many)!"

You might also visit www.everydayhealth.com/copd/copd-basics.aspx for more information!

We Are In Control Now!

On June 22, 2009, President Obama signed the Family Smoking Prevention and Tobacco Control Act into law. The Food and Drug Administration (FDA) now has the authority to regulate the manufacturing, advertising and promotion of tobacco products – specifically marketing designed to mislead consumers or recruit young smokers. The House of Representatives passed this legislation by a vote of 298 to 112 earlier this year. The Senate vote was 79 to 17. It is estimated that the legislation will result in an 11% decline in underage smoking over the next decade and will significantly reduce the annual $100 billion cost for tobacco-related illnesses in the U.S.

Although the law will not allow the FDA to ban tobacco entirely, the legislation specifically allows the agency to ban candy-flavored cigarettes and tobacco marketing and sales to children. It requires disclosure of the contents of tobacco products and mandates changes such as the removal of harmful ingredients. Maybe we can now appeal to film makers. It has been found that taking part in team sports lowers the odds of children smoking, but it can't compete with the powerful influence of smoking in movies, a new study finds. Researchers say as many as 50 percent of adolescent smokers attribute their smoking to seeing it in films.

The new law prohibits terms such as "light," "mild" and "low-tar" that mislead consumers into believing that certain cigarettes are safer than others. The tobacco companies must now use larger, more effective health warnings on their products. Health care groups and associations could not be happier over this news!

Calling Dr. Bauer ...

Dr. Michael Bauer

Dear Dr Bauer:

How and why does a damaged respiratory system make a lot of mucus? I am not talking about an infection, but on a daily basis!

MS, Aurora, CO

Despite its reputation as something nasty, pulmonary mucus (sputum) serves a very useful purpose. The surface of the larger airways and bronchial tubes in our lungs are interspersed with special mucus-secreting cells that are active 24 hours a day. Normally, the lungs secrete about a tablespoon of mucus every day. This mucus coats and lubricates the surface of the bronchial tubes. The surface cells in our bronchial tubes also have billions and billions of surface hair-like structures called cilia that beat in a uniform manner through the mucus. These cilia in the mucus help rid the lungs of the millions of bad particles we inhale every day such as air pollution, bacteria, pollens and dusts, and smoke particulates. Mucus is our friend (most of the time)!

Infection such as bronchitis or pneumonia is not the only cause of increased mucus production. In other words, lots of mucus, even if it's yellow or green, doesn't necessarily mean you have an infection. Anything that irritates the lung will cause an increase in mucus production. Daily exposures to air pollution and cigarette smoke are common triggers. Sometimes scars in the lung act as focal points of irritation and cause more mucus production. This is the underlying problem with bronchiectasis. A more uncommon type of lung cancer called bronchoalveolar cancer is associated with marked sputum production. Genetic diseases such as cystic fibrosis cause abnormal production of mucus.

Fortunately, we have lots of medications and treatments to control excessive mucus production!

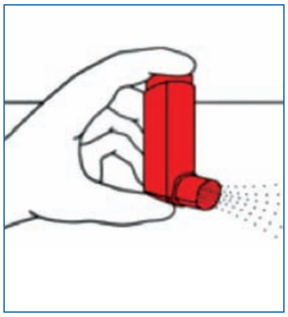
Question for Dr. Bauer? You may write to him at The Pulmonary Paper, PO Box 877, Ormond Beach, FL 32175 or by email at info@pulmonarypaper.org.

Dr. B's Big Adventure!

Dr. Bauer is a very passionate trout fisherman! What's your passion?

Know Your Inhalers

The American College of Chest Physicians want you to be aware of the difference between the old CFC inhalers compared with the HFA inhalers now in production. To get the prescribed medication, remember to use proper technique. Make sure you follow the proper priming instructions that come with each inhaler – most require 2 to 3 actuations. The HFA inhalers have a weaker spray and a softer mist, and require a slower inhalation. Make sure the opening is not clogged or you won't receive all of the medication.



After removing the metal canister, the mouthpiece should be cleaned weekly by running warm water through the top and bottom for 30 seconds. Shake the container to remove excessive water and let air dry.

Unfortunately, the HFA inhalers are more expensive. Generic equivalents will not be available until after 2012, but you may check the manufacturers' web sites for discounts. Some contain a small amount of ethanol. If tested within 10 minutes after use, you may have a positive alcohol breath test!

If your inhaler has a dose counter to keep track of how much medication is left, it has a much shorter expiration life because it may let in water vapor more readily. It expires 60 days from your first use, compared to 15 to 24 months for most other brands. If water vapor enters the canister, it will decrease its effectiveness.

Fibrosis File

Blood Test Alerts Physicians of IPF Decline

The American Journal of Respiratory and Critical Care Medicine reports investigators have identified proteins that could prove to be the first biomarker blood tests able to identify idiopathic pulmonary fibrosis (IPF) patients at risk for sudden deterioration of lung function. For most IPF patients, the lung-scarring disease progresses gradually and lung function slowly deteriorates. But some IPF patients decline rapidly, causing diffuse damage of the lung alveoli.

Researchers discovered levels of a protein called alpha-defensin to be high in patients experiencing exacerbations. There was no evidence that infection or inflammation was the cause of disease acceleration. Research will now work to identify these patients so they may receive more aggressive therapies.

IPF Support Groups Develop Helpful Bonds

Joe Walsh of Denver is proud of his Idiopathic Pulmonary Fibrosis (IPF) Support group. This November, they will begin their third year of interaction at Exempla Rehabilitation Center in Wheatridge, Colorado. Joe tells us, "Our format is one of an open forum in which a large variety of topics are discussed. We come together once a month to seek answers, share concerns, and once in a while have some 'feel good laughter.' One of our members created an Internet website, www.ilddiscuss.com, with an open forum for discussion. Please take the time to visit our website and share your questions, comments and concerns. Our mission is "to educate, inform, support and build hope for the individuals and families living with pulmonary fibrosis."

To locate a group in your area, visit The Coalition for Pulmonary Fibrosis (CPF) website at www.coalitionforpf.org or call 1-888-222-8541. The CPF reports our legislative effort remains a primary focus for us. We have 32 co-sponsors on our bill, H.R. 1079, and are working to secure two senators to co-sponsor a bill in the Senate. The bill will increase funding for research into IPF.

CPF is also awaiting news on the progress of the FDA application for Pirfenidone, which if accepted, will make it the first approved treatment for pulmonary fibrosis. InterMune, Inc. recently announced results from two Phase 3 CAPACITY studies evaluating Pirfenidone in patients with IPF. The primary endpoint of change in percent predicted Forced Vital Capacity was statistically significant.

Join others who are living with pulmonary fibrosis on a ten day cruise, leaving Los Angeles to the Mexican Riviera on January 30, 2010. For more information, visit www.seapuffers.com.

Ask Mark …

Mark Mangus, RRT
EFFORTS Board

Laura from New Mexico writes, “I use Albuterol/Ipratropium Bromide in my nebulizer upon awakening and then within 15 minutes I use the Advair Discus. Is this the proper thing to do or should I wait at least two hours before using the Advair?” Jana from Louisiana also asks about proper spacing between Foradil and Spiriva.

Mark advises, “If your breathing isn't too severe an issue when you awaken, try using the Advair first. If you're using Spiriva, you should take it a few minutes after the Advair. If after 30 minutes to an hour, you still aren't breathing well, then go ahead and use the Albuterol/Ipratropium Bromide. Ultimately, if you can put the Advair (and Spiriva, if taken, too) before the Albuterol/Ipratropium Bromide, you should find that you need less of the Albuterol solution in the long run.

There is no need for any ‘special spacing’ considerations with regard to time between Foradil and Spiriva. They can be taken a few minutes apart, if you like. I recommend against waiting any longer than 30 minutes between them. Be sure to try to keep as close to 12 hours between the two doses of Foradil. Some folks take it when they first get up and then not again until they go to bed. That often results in intervals between doses of 16 hours and 8 hours.”

John from Florida writes, “I just came in from mowing the lawn. My O_2 saturation was 93% and my pulse was 120. What is the maximum pulse rate that would be considered dangerous? Sometimes I just can't do slow pursed-lip breathing!”

Mark explains, “The classic formula for figuring your maximum heart rate is 220 minus your age. A 70 year old would have a maximum heart rate of 150. If you multiply this number by 60% to 80%, you will find your target range, which would be 90 to 120. The upper end would be considered your “danger threshold.” This number is only your predicted danger point. You may be in trouble earlier or not have to worry until your heart rate is much higher.

All of those numbers must be modified with “how you feel”. If you are feeling ill, numbers go out the window and symptoms must prevail. If you were simply tired, winded and otherwise OK, then you likely faced no harm or problems. This information is all barring other problems you have that we are not aware of. Your doctor can best tell you which of these choices fits your picture.

It is not necessary to breathe in through your nose, especially if you are huffing and puffing with exertion. How you get the air “in” has no importance, compared to that of blowing out. Pursed-lip breathing (PLB) is all about getting the air “out” of your lungs.

A common misconception is that whenever you do PLB, you must always strive for slow inhalation and long exhalations. What you can and should do is blow out through pursed lips when you breathe fast. You want to slow your exhalations down and achieve comfort along the way. Slow is not the operative word when you are exerting or exercising! To try to breathe too slowly is counterproductive and can easily add to your anxiety/panic.”

Laura asks if there is a COPD diet while battling high cholesterol.

Mark replies, “You have asked the million dollar question! One does not necessarily have high cholesterol because of consumption of any given food. Unfortunately, there is no sure-fire COPD diet to recommend. Just as so many have multiple conditions and individual differences, one cannot say that one given diet is good for everyone. We can only recommend broad modifications according to conditions and circumstances. For every health problem one has along with their COPD, dietary needs change. The Cleveland Clinic and National Jewish Health websites can only make recommendations that are broad and leave it to the reader to decide what applies.”

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.

Feelings

It always helps to vent! If you or your caregiver would like to write about how you really feel about any aspect of chronic lung disease, we will credit you with a year's membership. Please send to: The Pulmonary Paper, PO Box 877, Ormond Beach, FL 32175.

I struggled for two years to find out what the vague symptoms I had were. In 1981, I found out that I had Scleroderma and after 11 years developed pulmonary fibrosis. Treatment with Cyclophosphamide alleviated my breathing difficulties but in 2006, I was put on oxygen therapy. I am not a "Pollyanna" but I don't have the 'Why me's?' either. I find that finding some small thing to be grateful for helps me get through each day. I have a rolling backpack like the kids use. It holds my two small B tanks and other travel needs.

My feelings are all mixed up sometimes. I am grateful that oxygen is available for me to use but angry that I have to use it. Strangely though, I am not unhappy!

Gloria Ramos, Brooklyn, NY

Karen Buck leads her pulmonary rehabilitation class in Cheyenne, WY, in harmonica lessons!

Would you like to have The Pulmonary Paper sent to you via email? Send a request to cbelyea@pulmonarypaper.org.

Sharing the Health

Ruth McClellan of Manchester, NH, was standing at a grocery counter when a young girl kept staring at her oxygen cannula. She finally turned to her Mom and very seriously asked, "Mom, is that lady a cat?" When she stopped laughing, Ruth explained to the little girl what oxygen therapy is all about!

I am 82 years old and have used oxygen for nine years at a setting of 2.5 LPM. I was interested to read about dynamic hyperinflation in your last newsletter. I faithfully practice pursed-lip breathing – inhaling for 4 seconds and exhaling for 8 through puckered lips – and don't seem to have this problem anymore. I also like to have fun with my oxygen. When I went on a bus trip during the holidays, I put red leg warmers on my tanks, put them in a styrofoam cooler that I wrapped in Christmas paper and stuck a huge red bow on the top. I used a pull cart and bungee cord and had a fun time!

Dolores Soldo, Flinton, PA

At night I find myself waking up with a very dry mouth from my medications and CPAP machine. Sugar-free cough drops have helped me, and I noticed they also cut down on the amount of mucus I have. If you have problems of this sort, I highly recommend them!

Janet McLees, Flint, MI

To straighten out cannulas, hang them over the hooks on the bathroom door so the heat and steam will uncurl them. I wear aprons with pockets to help me carry items around the house. I do my housework in pieces and shop for groceries the same way. (I have to carry bags up a dozen stairs.) I leave heavier items in the car and ask visitors to bring them up the stairs. I keep a plastic bag on the car seat so I can swivel in and out easier. As long as I have a shopping cart to lean on, I'm good for hours!

Constance Monahan, Fremont, NH

Receive a Free One Year Membership

Contribute a picture or tip on how you COPE with COPD! Send to The Pulmonary Paper, PO Box 877, Ormond Beach, FL 32175. Include your name and address.

I recently took a bus trip to the Chicago Botanic Gardens. Not wanting to carry my portable oxygen tank, I slid it into a backpack on wheels. Not only did the backpack hold my tank, it also contained a rain poncho and my wallet – everything I might need while at the Gardens. I could push and pull the backpack along as I walked on the paths. Next time, I am going to put longer tubing on the tank. Hope my idea helps others!

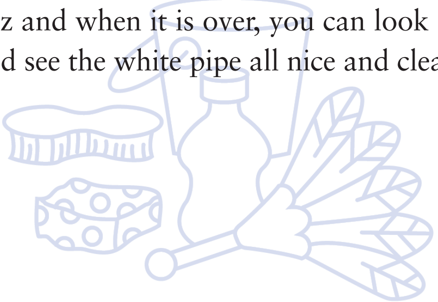
Kathy McCarthy, Appleton, WI

I need encouragement to exercise. At one time, we had a pulmonary rehabilitation program available, but not any more. I found a wonderful support group on the Internet at www.copd-support.com. You can sign up for their exercise group called Let's Get Fit and also for their online newsletter.

The Let's Get Fit groups are small, mine has five members. We email each other daily to keep up with the exercise we are doing – it really helps me keep going! Without this group of dear friends, I might have quit a long time ago. I have not only lost weight, I have more stamina, so it is a great pay off!

Alice Lutfallah, Des Plaines, IA

Ida C. tells us, "I am unable to use bleach and have recently read that white vinegar is a great disinfectant. It works just great! Put baking soda down your kitchen and bath drains, followed by vinegar. It will bubble and fizz and when it is over, you can look down your sinks and see the white pipe all nice and clean again!"



I was a bar singer in the 1940s and 1950s, so music has been a part of my life for many years. I sing every night before I go to bed. I start with George M. Cohan, Ira Gershwin and all the writers of the Age of Innocence. I usually sing between 15 and 30 songs. I sing Irish and contemporary music – Al Jolson, Cohan, Dennis Day, Phil Harris, Sinatra and others. This self concert has helped me breathe better and, I think, reduced my dependence on inhalers. I am 81 years old, diagnosed with COPD in 1998 and have used oxygen since 2002.

Guy Brock Sr., Davenport, IA

To make handling heavy oxygen bottles easier, I use a pet carrier on rollers. The mesh panel allows liquid oxygen to breathe and you have room for other supplies you may need!

Nancy Stearns, Riverton, WY

On a recent SeaPuffer cruise, we talked about exacerbations of COPD – which is the fancy name for a worsening of your condition, like getting a respiratory infection or pneumonia and ending up in the hospital. Chris Wigley said he likes to call them "exasperations" instead! Chris and his wife Gwen are very active in an Internet group, www.COPDCanada.ca. Gwen also publishes the group's newsletter!

Mary Jane Gromley of Bloomington, IN, tells us when she wears a regular N95 mask when she is out in crowds, she feels intensely conscious of rebreathing her own air. She found N95 masks with exhalation valves at her local Lowes store for about $4 and feels they are worth the extra price.

Mary Jane also advises those who take any inhaler to "RGS – Rinse, Gargle and Spit" after their use, not just when using those that contain a steroid. She feels she is not so jittery and shaky now. She is off to make a presentation on the benefits of playing the harmonica for people with lung disease at the annual convention of the SPAH – Society for the Preservation and Advancement of the Harmonica.

U.S. health officials have warned consumers to stop using Zicam nasal cold remedy products because they can cause the loss of a sense of smell. The specific products contained in the warning include Zicam Cold Remedy Nasal Gel, Zicam Cold Remedy Nasal Swabs, and Zicam Cold Remedy Swabs Kids' Size.

I always woke up with marks on my face from my oxygen cannula. My oxygen supplier gave me gray foam cushions that are split, designed to be used over your ears to prevent pressure sores. I instead slid them down the tubing over my cheeks and I no longer have the morning marks!

Suzanne Prinz, Albuquerque, NM

Every good weather day I go to our local pool. When there, I gather up a noodle, a pair of water weights and place them at the edge of the pool. Then I take my liquid oxygen, hold it up as I go down the steps and into the pool. When I am in, I set the oxygen at the edge with the equipment. After I get my breath, I take off the oxygen, straddle the noodle and start paddling. First I go backwards, then alternate my exercise by pedaling like I was on a bike forward, then backwards for 30 to 40 minutes. Then I use the water weights for 10 to 15 minutes. I have an oximeter, so I am able to test myself to make sure my oxygen saturation doesn't get too low without using oxygen. I keep talking to a minimum. My legs and arms have become much stronger, I have more energy, I have kept myself from deteriorating, and am getting a good tan!

Barbara DiPaolo, The Villages, FL

Jay Schnitzer of San Francisco, California has found a stair lift has made his life a lot easier.

Getting into using oxygen 24/7 was a huge confrontation for Lois Perelman, so she made a video about how she felt about it. You may see it at www.youtube.com/watch?v=DxJrLrqJ2nw. If you do a search on this site for COPD or another respiratory diagnosis, you will be surprised what you will find!

Traveling Tales

I live in the Denver area, and often travel through the mountains to see family in Western Colorado and to vacation at moderate (6000 to 7000 feet) elevations in the state.

I am on continuous 4LPM. Neither my POC (portable oxygen concentrator), nor my "demand" type liquid O2 portable, can sustain me at elevations above about 7000 feet. When going over the passes (10,000 feet), I switch to gaseous O_2 from an E-size cylinder, or if I will be staying for a significant duration, I use a continuous flow liquid oxygen tank (Companion 1000), which I can refill from a PB21 travel reservoir. If I am likely to need cylinders or the reservoir refilled, I make arrangements with local companies through my oxygen provider. In winter, when very long traffic delays are possible, I always carry a pair of spare E-cylinders.

Joe Donathan, Denver, CO

Mary from Florida writes, "While traveling with a portable oxygen concentrator, a flight attendant kept eyeing me suspiciously. Right before the door to the aircraft was closed, she came to my seat and said, 'I just wanted to check – that unit acts like a tank and is under pressure, right?' I said no, and she winked and said she just wanted to be sure! This ridiculous exchange proves we have to stay on our toes!"

Thank you for the recommendation of bringing along an extension plug to the airport to share electricity with all the computer users. It certainly has made my life easier! Jack O, Chicago, IL

Planning on traveling with oxygen to a foreign country and don't know where to start? Go to the site www.breathineasy.com and search for the area that you are visiting. You may also purchase their guide to finding oxygen on over 1,700 cities around the world. The cost is $29.95 which includes shipping and may also be ordered by calling 1-925-891-5017. **Jack D, MA**

I used to feel self conscious about being pushed in a wheelchair. One exception is when I am traveling in an airport! The wheelchair gets you special treatment and often you are able to go through much shorter lines at security checkpoints. You can also board the plane before everyone else so that you have a little more time to get situated in your seat. Request wheelchair assistance when you make your reservation and there will be an employee who will push you in your own or their transport chairs. I bought mine from a local drugstore at a very reasonable price and often take it to the mall. I get behind it and push it myself and am able to put my packages in it! Betty Bell, Denver, CO

Simple Blood Tests for Alpha-1 Emphysema

Alpha-1 antitrypsin is a protein in the blood that it is produced in liver cells. When you don't have enough of this protein, it may result in Alpha-1 Emphysema. If you have developed your lung problems at an early age, you and members of your family should be tested to see if you have the deficiency. Proponents believe every person with lung problems should be tested.

According to University of Florida researchers, "Diagnosis for the genetic form of emphysema is made by a simple blood test. Three programs offer this testing at no charge.

State of Florida Alpha-1 Detection Program: The State of Florida and the Alpha-1 Foundation have sponsored this detection program since 1999. The program focuses on targeted population screening, patient and physician education, and treatment programs for AAT Deficiency. To order a free test kit, call the University of Florida Alpha-1 Research Program toll-free at 1-800-559-5706.

Talecris Biotherapeutics Alpha-1 Detection Program: Talecris Biotherapeutics is supporting a nationwide targeted detection program for Alpha-1. Test kits and laboratory processing are provided to pulmonary clinics and at-risk patients free of charge. To obtain a Talecris Alpha-1 test kit, call 1-800-562-7222.

Alpha-1 Coded Testing (ACT) Trial: The Medical University of South Carolina is currently conducting a research study which evaluates perceived risks and benefits of genetic testing. The Alpha-1 Coded Testing (ACT) Trial offers free and confidential finger-stick testing for Alpha-1 Antitrypsin Deficiency. The test can be completed at home and results are mailed to the participant's home. Anyone can request to be tested. Participants or the participant's guardian must submit a short pre- and post-test questionnaire. For more information, visit www.alphaoneregistry.org/test_kit/home.html or call 1-877-886-2383.

The finger stick collection system utilized by these programs requires only a small prick to the finger and a few drops of blood on the test card. The sample is sent to the lab for processing and results are typically ready in two weeks.

For questions regarding any of these programs, call 1-866-284-2708 or alpha1lab@alphaone.ufl.edu. To learn more about the disease, visit www.alphanet.org to see the *Big Fat Reference Guide* and *Skinny Little Reference Guides*.

Product Corner

New Portable Liquid O_2 Device Hits Market

GoLox is a new portable liquid oxygen device from Phillips Respironics. Weighing almost 4 pounds when full, it is said to last for 10 hours on a setting of 2. The unit has one continuous flow setting of 2LPM which will last for 2.5 hours. There are six different pulse dose settings delivering from 12 to 48 cc/breath. It is 7.25 inches high and 7 inches wide.

Because it automatically stops when full, there is less chance of freezing when refilling the unit – thanks to a new patent-pending valve. It typically takes 40 seconds to fill the GoLox. It is compatible with most top-fill liquid reservoirs. You are able to use a regular cannula with this device. There are no batteries or maintenance involved with the GoLox.

Ask your oxygen supplier about the availability of the GoLox in your area. It is available for purchase for approximately $1,200 and comes with the carrying case shown here. For more information, visit http://golox.respironics.com.

E-Cigarettes: Go Away!

The testing of electronic cigarettes, known as e-cigarettes, has shown that they contain cancer-causing chemicals and other toxins, including diethylene glycol, used in antifreeze. E-cigarettes are battery-operated devices that contain cartridges filled with nicotine, flavorings and other chemicals. The device turns nicotine, which we know is highly addictive, into a vapor that is inhaled. Instead of helping people stop smoking, e-cigarettes seem to be doing the opposite!

Public health experts have expressed concerns about the safety of these products which are manufactured in China. They are a nicotine delivery device with no quality control. A big concern of health experts is that e-cigarettes are marketed and sold to young people. The devices are available online and in shopping malls. The cartridges for e-cigarettes are available in flavors, including chocolate, mint and bubblegum.

2009–2010 Flu Season Vaccine Update

The FDA has approved the vaccine to protect against the 2009–2010 seasonal flu. People need to get vaccinated each year because the strains of circulating flu differ each year. This year you may be getting two injections. A separate vaccine to protect against H1N1 swine flu is now under development and about to undergo testing. The swine flu vaccine is expected to be available some time in the fall. The US Health and Human Services would like to bring the swine flu vaccination campaign into schools and community centers when it is available.

If you would like to get technical, this year's vaccine contains: an A/Brisbane/59/2007 (H1N1)-like virus; an A/Brisbane/10/2007 (H3N2)-like virus and a B/Brisbane/60/2008-like virus.

Getting immunized is recommended for children 6 months up to 19 years old, pregnant women, anyone 50 and older, people with chronic medical conditions, people living in nursing homes and other long-term care facilities, and people who live with or care for those at high risk for complications from the flu.

The FDA says people should start getting vaccinated for seasonal flu in September and October. No vaccine is 100 percent effective, but it's the best protection against flu and can prevent many illnesses and deaths.

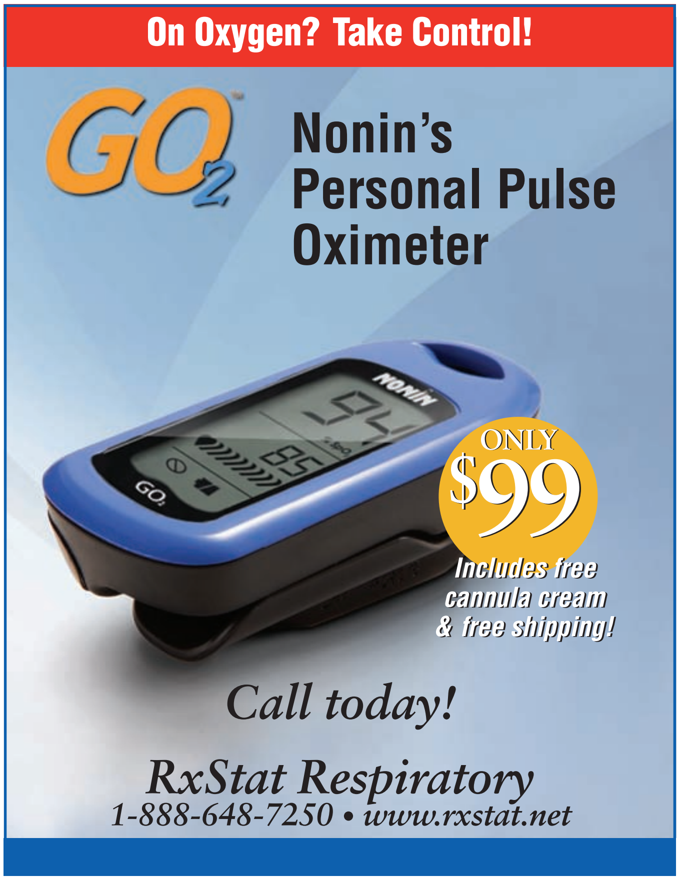
Don’t Be A Difficult Patient!

People often tell us it is difficult to talk to their doctor but does your doctor think you are difficult too? According to ABC News, these are the bad habits that will brand you as a “difficult” patient: Withholding information about your condition; stopping your medications; always looking for an “easy way out” – not willing to change your lifestyle; insisting you need unnecessary drugs and tests; and bringing a crowd to your appointment.

COPD: An Equal Opportunity Disease

Lori Palermo of Pennsylvania wants all women to know COPD now kills and hospitalizes more women than men every year. If this trend continues, the Centers for Disease Control projects COPD to become the third-leading cause of death worldwide by 2030. You can find out more at www.LearnAboutCOPD.org.

Lori also wants you to know about an informative book available at www.amazon.com titled, *Understanding COPD: Chronic Obstructive Pulmonary Disease,* by Dr. Daniel Lee.



The Pulmonary Paper
PO Box 877, Ormond Beach, FL 32175-0877
Dedicated to Respiratory Health Care

**Non-Profit
Organization
US Postage
PAID
Ormond Beach, FL
Permit #100**

Respiratory News

Researchers from Australia found eating lots of soy products may improve lung function and reduce the risk of developing COPD and other respiratory symptoms. Flavonoids in soy act as an anti-inflammatory agent in the lung and may protect against tobacco carcinogens for smokers. Soy is found in many Japanese foods, including tofu, natto, miso soup, bean sprouts and soy milk. Previous research has shown that soy foods can also reduce cholesterol and alleviate menopause symptoms. The study was published in the journal *Respiratory Research*.

The American Academy of Sleep Medicine recommends oral appliances for patients with mild-to-moderate obstructive sleep apnea who are not appropriate candidates for positive airway pressure masks or who have not been helped by its use. Most dental devices are acrylic and fit inside your mouth, much like an athletic mouth guard. Others fit around your head and chin to adjust the position of the lower jaw. They open your airway by bringing the lower jaw or tongue forward during sleep.

A new drug Iressa (gefitinib), which now has its European license, is designed to treat "non-small" cell lung cancer. In clinical trials, gefitinib has been shown to slow the growth of cancer in about one in ten of these patients who carry a mutated form of a gene that controls cell growth. Manufacturer AstraZeneca emphasized that the expensive pill will only benefit a select proportion of patients. Studies in Asia suggest that 25 percent of suitable patients taking Iressa survived at least a year with "no disease progression," compared with only 7 percent given standard chemotherapy treatment.

Scientists may some day be able to fight lung cancer using gene therapy delivered by an inhalable spray. In a new study in *American Journal of Respiratory and Critical Care Medicine,* mice with lung cancer that were treated with a vaporized viral vector twice a week for four weeks had fewer, smaller tumors than untreated mice.