The Pulmonary Paper

May/June 2008

Dedicated to Respiratory Health Care

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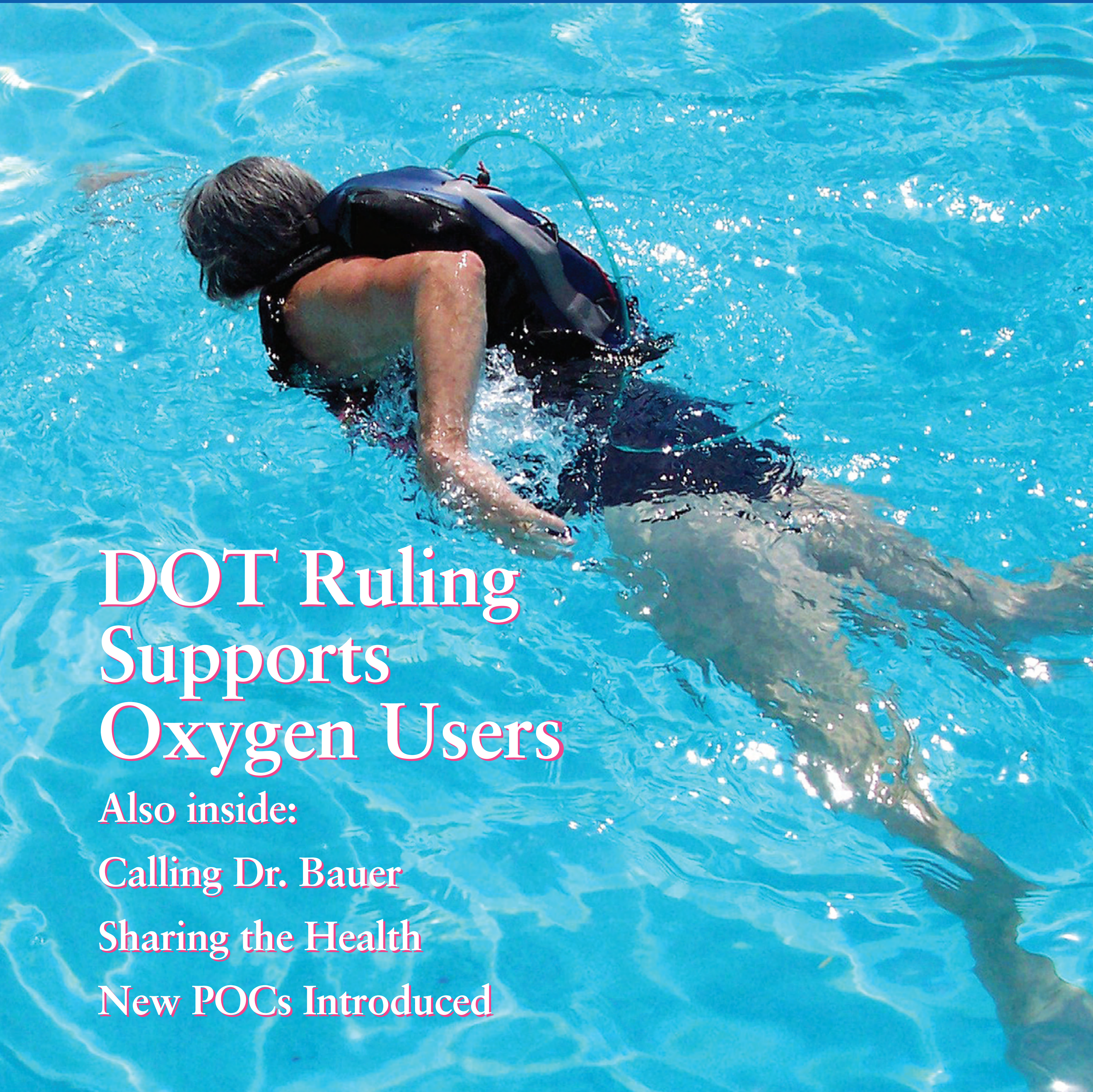

DOT Ruling Supports Oxygen Users

Also inside:

Calling Dr. Bauer

Sharing the Health

New POCs Introduced

The Pulmonary Paper
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As we cannot assume responsibility, please contact your physician before changing your treatment schedule.

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Roxlyn Cole of Colorado tests an oxygen swimming pack prototype (cover photo). If you are interested, call LifeBack Carrier™ at 1-970-257-1866.

Ah, summer – what power you have to make us suffer and like it.” – Russell Baker

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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.

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Left to right: Dr. Michael Bauer, Celeste Belyea, Dom Coppolo

It does not seem possible that 20 years have gone by since I bought a small computer to try and connect people who have chronic lung problems. Dr. Mike Bauer and Dominic Coppolo have been with me since the beginning. Living in different parts of the country, we had the rare opportunity to get together recently at a medical meeting. There is something special about long friendships and I truly appreciate theirs. If you have not connected with an old friend in a while, maybe it can be part of your summer vacation plans!

Celeste

Home Oxygen and Equipment:
Legislative Update

About 1.2 million people who are Medicare beneficiaries use oxygen. January 2009 is right around the corner and as we go to press, there have been no changes to the ruling that you will own your oxygen concentrator after three years of Medicare payments. If you were using oxygen on January 1, 2006, the concentrator that is in your home on January 1, 2009, will be your property. You will be responsible for its care and maintenance. We have been writing our Senators and Representatives to support HR 621/S 1484 which would, if enacted, repeal the 36-month oxygen equipment ownership provision.

There is another concern in the arena of oxygen reimbursement that will affect us. Kitty Collins, RRT, Coordinator of Seton Outpatient Pulmonary Rehabilitation, Austin, TX, explains, “The Medicare Modernization Act is changing the home medical equipment industry through the implementation of a competitive bidding program. The program involves oxygen supplies and other respiratory equipment. The winning amounts will replace the current payment amounts your supplier receives. Contracts will be awarded to a sufficient number of winning bidders in each area to ensure access to, and service for, high quality medical equipment items.”

“This year, as early as July 2008, competitive bidding will begin in ten cities and surrounding areas which include Charlotte (NC and SC); Cincinnati (OH, KY and IN); Cleveland (OH); Dallas (TX); Kansas City (MO and KS); Miami (FL); Orlando (FL); Pittsburgh (PA); Riverside (CA) and San Juan (PR). The program will be expanded to 70 additional areas in 2009. When fully implemented in 2010, it is projected that these savings to Medicare will amount to $1 billion annually.”

“For people whose link to staying active is easy access to portable oxygen, those government savings are small comfort. Oxygen providers that survive the bidding process may need to cut back on services as well as decrease the number of licensed personnel to provide services. With fewer companies providing oxygen delivery, the number of people and the area they cover will increase. This may make it more difficult for patients to receive services and supplies in a timely manner.”

If you live in one of the initial competitive bidding areas, and your oxygen supplier submits a winning bid, you probably will not notice a change in service. If your supplier is not a winning bidder, they either have to accept the reduced payment or lose you as a customer. If this is the case, you will be given a list of suppliers that submitted winning bids to choose a new company. The type of equipment you use should not change. (If you are used to liquid oxygen and a lightweight portable, the new company should supply you with it.)

Many in the home medical business feel that the large nationwide oxygen providers, such as Lincare, Apria, and American Home Patient, may seek to purchase the smaller companies that have won the competitive bids.

Readers Asked about Letairis™ for PH

In our last issue, we discussed Pulmonary Hypertension. Many readers wrote to tell us we had not talked about a medication they were currently taking for their condition called ambrisentan or Letairis™ tablets.

Letairis prevents thickening of the blood vessels in the lungs and heart. It helps to lower blood pressure and lets your heart pump blood more efficiently. Letairis works to improve your ability to exercise and prevents your condition from getting worse. The most common side effects include lowering of red blood cell count, swelling of hands, legs, ankles and feet, stuffy nose, flushing and palpitations. The drug can also cause liver problems and serious birth defects.

If you have pulmonary hypertension, ask your physician if this drug may be right for you!

Calling Dr. Bauer ...

Dr. Michael Bauer

Dear Dr Bauer,

I have emphysema and chronic bronchitis and many of my prescriptions say, "You should not drink alcoholic beverages while taking these medicines." I am in a serious quandary as I enjoy one shot of Jack Daniels every evening. (It's like Jack Benny being held up by a thief demanding his money or his life and pondering what to do!) Can you grant me dispensation for one shot per night or what are the serious consequences if I continue the pills with this libation that gives me a glow?

Anxiously Yours, ABM, CA

Your question is a good one, and I suspect there may be many readers with lung disease who also have the inclination to partake of alcoholic beverages on a regular basis. Why might alcohol have effects on medications? We all know that alcohol can seriously injure the liver, especially when moderate amounts are taken on an every day basis. What you may not realize, however, is that many medications taken for the treatment of lung disease are filtered and removed from the body by important chemical reactions that occur in the liver. If the liver is not working properly, medications like theophylline may reach dangerously high levels in the bloodstream with serious side effects.

What then is a safe amount of alcohol? Dr. Bauer can't answer that one with certainty. In moderation, most people with lung disease can enjoy an alcoholic beverage without bad side effects. Unfortunately, one's definition of moderation is often clouded by the opinion of who is asking and who is answering the question! Anyone with liver disease, such as cirrhosis or hepatitis, could certainly have serious reactions when mixing alcohol and medications. Those readers who generally feel well and have no liver disease should check with their doctor and then will likely be able to enjoy an occasional shot of Jack Daniels.

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

Fibrosis File

Researchers from Japan may have a new treatment option for people with Idiopathic Pulmonary Fibrosis (IPF). Information presented at a recent American Thoracic Society Conference in Toronto involved a Phase III clinical trial in which investigators discovered that a daily dose of pirfenidone could improve lung function and slow the progression of IPF.

"The most common treatment for IPF is anti-inflammatory agents such as steroids," said lead researcher Takashi Ogura, M.D. "However, our study confirmed that pirfenidone, the main action of which is thought to be antifibrotic, achieved a therapeutic effect on IPF. I expect that our study will serve as a guide to develop a new therapy for IPF in the future."

Pirfenidone may also be able to treat other fibrotic lung diseases, such as interstitial pneumonia. A larger, multi-center trial using the drug is currently underway in Europe and North America with results expected later this year. Pirfenidone has received fast track designation from the FDA, a designation used for a drug that shows promise to treat a serious or life threatening condition. The FDA facilitates the development and expedites the approval applications for fast track products.

The Coalition for Pulmonary Fibrosis (CPF–www.coalitionforpf.org) is pleased to announce a new bill will be proposed in the House of Representatives by Congressmen Brian Baird (D-WA) and Mike Castle (R-DE) in early June. It will be known as the Pulmonary Fibrosis Research Enhancement Act. Its purpose is to expand the research, prevention and awareness activities of the Centers for Disease Control and Prevention and the National Institutes of Health with respect to pulmonary fibrosis. The CPF is encouraging all patients and their families and friends affected by IPF to write their member of Congress to express their support for this effort. Please visit the CPF web page for more information, or contact Teresa Geiger at (888) 222-8541 to learn how you can help!

The CPF reports that Hollywood has been taking notice of pulmonary fibrosis! As many people die each year of pulmonary fibrosis as of breast cancer, yet the disease is vastly unknown.

The recent controversial Michael Moore film, *Sicko,* featured pulmonary fibrosis patients including Vito Valenti, a 9/11 responder and CPF volunteer and advocate. Fox TV's *House* medical drama aired two shows last season that included pulmonary fibrosis diagnoses or suspicions. TNT's *Heartland* medical drama features actor Dabney Coleman, whose character suffers from pulmonary fibrosis and uses supplemental oxygen in the series. Hollywood celebrities to succumb from pulmonary fibrosis include Evel Knievel, Robert Goulet, Marlon Brando, James Doohan (Scotty of *Star Trek*), Gordon Jump (Maytag Repairman) and *Jaws* author, Peter Benchley.

Ask Mark …

Mark Mangus, RRT
EFFORTS Board

Mary Ann from Florida asks, I have heard Muscle Trainers are good for people with lung disease. Can you tell me about them?

Mark says, Inspiratory Muscle Training (IMT) is a nice and sometimes useful adjunct breathing exercise for folks with COPD. Electrical muscle studies done about 15 years ago showed that intercostal and upper chest accessory muscles are actually normal to above normal strength and not clinically in need of "strengthening". There is a certain amount of muscle activity that is not coordinated and with many COPDers, during stressed breathing, it seems to help with that aspect. *The Guidelines to Management of COPD* concluded from an analysis of studies of IMT, that while it doesn't statistically render meaningful change or benefit as a stand alone therapy, since it does not harm, it can be useful to include with a comprehensive exercise program for pulmonary rehabilitation. They stated they could not 'recommend' it as necessary part of a program because it did not make a consequential difference.

I recommend getting a few coffee stirrers that are the straw or dual small-lumen tube type. Try inhaling though them before spending money on commercial devices. You can use the stirrers for both inspiratory and expiratory muscle exercise and training.

Francine from Texas wondered if she could nebulize her Albuterol and/or Duoneb medications at the same time with her Pulmicort.

Mark advises, You could nebulize both solutions mixed together but I see two concerns. First, your treatment would last a very long time, as that is a lot of solution to nebulize. Second, and more importantly, your nebulizer breaks the medication into ideal particle sizes that will allow them to be deposited into your lung. When the medictions are mixed together, the particle size may be altered. It is advisable to nebulize the Pulmicort separately from the others, in a cleaned or different nebulizer cup.

Larry, from EFFORTS, tells Mark having little money and no health insurance make it a challenge to deal with his disease. Since I can't afford to get into a rehab program, I figured the best thing to do was set one up myself. Where can I get information on setting up my own rehab?

Mark replies, Rehab consists basically of two components: education and exercise. You'll learn about breathing techniques that improve your ability to control your ventilation and breathing comfort. You'll find out how to maintain the best state of health and function for the longest period of time, medications, treatments, nutrition, sexuality and resources for the various needs you encounter.

Exercise is the second component, which should get you up and moving again and slowly but surely push you to gain strength and endurance as well as improved function. Within your exercise efforts, you should be able to incorporate, practice and master those breathing techniques to reduce your struggle to do physical tasks, to gain control over anxiety caused by difficult breathing and to go about your daily life.

The tough part is monitoring your vital signs and oxygenation–unless you have the equipment to do it. You have to be confident enough to push yourself when you feel bad, knowing that doing so will not hurt you. You should know how much is OK and when you should hold or pull back. Those are the nuances that professional medical help provides at rehab. With your doctor's help, you could do it on your own!

Gary Bain, Founder
of EFFORTS

We are sorry to report the passing of EFFORTS founder, Gary Bain. His legacy of the online support group will live on and continue to connect those with chronic respiratory problems.

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.

Memories: Having lived with COPD for ten years, I often lament that I will never play golf again but have to remember the hundreds of rounds I did play and my two holes-in-one. Regretting that I can no longer lay in the sand or walk on the beach, I have to remember all the hazy, lazy days I spent at so many beautiful beaches. I rue the fact that I do not have female companionship but have to remember "all the girls I have loved before." And I have to remember that I alone am responsible for my condition and be thankful for the medical science and services that have kept me alive to have memories of better times. JB, Fort Myers, FL

I use my oxygen at 6 LPM most of the day and higher when walking. I can maintain my saturation at 90-91% sitting still at 2-3 LPM, but movement and talking requires more. I just finished raking an acre of lawn, (it took three days, three naps and six E tanks.) I do my laundry, shop, sit down for a minute at least four times to make my bed, but "I get 'er done!" I use my concentrator at home and 30 E and 30 D tanks a month at church, two Bible study groups, visiting shut-ins, and am now considering volunteer work at the VA. My trips are day trips as longer ones are not in my financial range. I enjoy and find extreme kindness and many, many infectious smiles coming my way that need returning, which keep my spirits up. I smoked a pack a day and I haven't wheezed at night, nor got that buzzing in my head and passed out from lack of oxygen for 12 years, since I quit. I cough only to raise "stuff" during infections.

My advice is to try Pulmonary Rehab and attend classes. You will find you feel so much better when you push yourself to greater heights. I signed up for a clinical trial at Dartmouth Hitchcock Medical Center. I not only get tested every three months to see how much I have improved, but I get paid for it!

I hear you when you try to justify why you should continue to smoke. I did the same thing through four hospital smoking cessation classes, one acupuncture session, every filter, patch and gum known to man, two hypnotists, a shrink, bets, and losing two wives to cancer, and finally simply said to myself "I no longer am a smoker. It will not kill me if I don't smoke, as it did not the time I went six months, so I must just do it!" I can honestly say that it was so much easier than I thought it would be and I think the secret was to not give myself a way out by saying, "I'll try. …" SS, Andover, NH

Sharing the Health

The diagnosis I have been given is Non-Specific Interstitial Pneumonia. I go to pulmonary rehab and wear oxygen 24/7. I desaturate while walking and require a non-rebreather mask to keep my oxygen saturation above 90%. I drive my car when my saturation is 94%. When I get in the car, I am using a Helios Marathon set at 6 LPM Continuous. To make my portable last longer, I change the setting to 5 Demand when I can. Often I am concentrating on traffic and forget to make the switch. My daughter found a timer on the Internet that is small enough to clip onto my keychain to help me remember to monitor my oxygen level and change settings as indicated. This has worked very well and avoided aborted shopping trips!

Merle Teschner, Rockaway, NJ

I am 83 years old and on full-time oxygen. Before I got into pulmonary rehab, I just existed – now I am living! Many years ago, I enjoyed dancing, so I decided to try it again. I now dance with my oxygen two nights a week and feel better than I have in years. I also enjoy drawing, another hobby of mine. I encourage everyone with lung disease to keep doing the things you enjoy!

Jim Wortchow, Idaho Falls, ID

Jim Wortchow cutting the rug with Fay Whitney!

Congratulations to Donna Teel of Portland, OR, who just received a new left lung! Donna was diagnosed with emphysema in 1995 and has been on supplemental oxygen for the last five years. Donna says, “The day after surgery when they took the ventilator tube out, I coughed, sputtered, choked and then I breathed! I thought either it worked or I died in surgery and went to heaven!”

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 am not thankful I have COPD but I thank God, my doctor, oxygen and Spiriva. Six years ago, I was a Clinque associate and could hardly make it through my shift. I went to therapy but balked at using oxygen. I was petrified that oxygen was a death sentence, now I know it is a life saver! I feel and look 10 years younger and I can work in my garden at least an hour a day.

My folding gardening seat holds my long-handled tools, plastic bags, fertilizer and soil. I can sit and have everything within reach. I have my oxygen in a backpack.

Jacquie McBride, Brockton, MA

I am on oxygen and Coumadin, a prescription blood thinner. I sometimes have very bad nose bleeds and found just the thing to do to stop them! I get a glass of very cold ice water and take a few big drinks of the cold water through a straw. The bleeding then stops!

Shirley Merkle, Crestview Hills, KY

Putting one foot in front of the other is hard sometimes, but considering the alternative, I do it! I buy a sponge mop at the dollar store and put the handle from my two-foot dust pan on it to clean the refrigerator. You can use it in the shower too. I also buy the sponges that have a long handle that you fill with liquid detergent, and use them to clean the microwave. It’s amazing how the extra few inches help!

Patricia Goff, LaGrange, IN

I have a tip to keep track of whether or not you have taken your dose of Advair. I check whether the number in the slot is odd or even and assign the time of day it is – AM or PM – and write it on the side of the Discus (AM = even number). For example, if it shows an even number, I know I haven’t taken the morning dose yet. My night dose will be an odd number. From then on just check the number and time of day and you will know if you have taken the dose. Hope this helps.

Jimmie Heusler

Hannah Leutz bowls a strike while Carl Hill and Richard Hullihen wait their turn!

Reggie Case, RRT, has found a way to get the Pulmonary Rehab group at LakeWest Hospital in Willoughby, OH, involved in sports again! She brings her Wii video game and everyone is able to take part in a little friendly competition. (We have heard of some groups that have formed Wii leagues.) Reggie says at home, all generations of her family participate for hours of fun. She thinks the Wii is beneficial for her own father, as it improves his range of motion with the benefit of socializing with family and friends.

In your March/April issue, you mentioned the *Consumer Reports* tests of air purifiers in their December 2007 and February 2008 issues. *Consumer Reports* did not test the IQAir Health Pro Plus, which is sold by many established allergy supply centers. The IQAir filters down to 0.003 microns. It removes many times more particulates than other air purifiers. I have used one for over four years. The unit is approximately $800 and $59 for the fine dust filter, but it has helped me a great deal. For more information, you might visit the website of California-based IQAir at www.iqair.us or phone 1-877-715-4247.

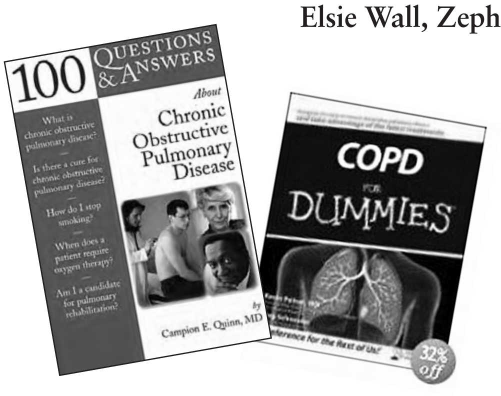
Henry Stern, Bronx, NY

I am part of a Better Breathers class that usually meets monthly. At the last meeting, a member came in and showed us the "Handy Air Tote" that she had. It is like a small suitcase, made to fit 2 B tanks with the tubing coming up through for use. I have not been able to locate the manufacturer or find out where to get one. Can anyone help?

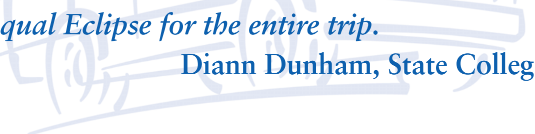
Verna Kublli, Hayward, CA

I found two books on COPD that may be of interest to our members. *COPD for Dummies* by Kevin Felner, MD and *100 Questions and Answers about COPD* by Campion E. Quinn, MD. They are both available from www.Amazon.com on the Internet at a cost of $13.59 and $11.53 respectively.

Elsie Wall, Zephyrhills, FL



The idea that you can't do things when you have to use oxygen is so wrong! You must take the initiative! (Even when your oxygen provider does not give you the best support!) My husband and I took a month-long car trip across the United States (almost 10,000 miles). I used my Sequal Eclipse for the entire trip.



Diann Dunham, State College, PA

Diann teaching her grandson how to use a slide!

For those with Inernet access, an excellent resource for caregivers explaining how to care for your loved ones at all stages of COPD may be downloaded at www.medicaring.org/educate/download/copdbook final.pdf

There is also a booklet available from your local American Lung Association office called *Caregivers Guide for Chronic Lung Disease.*

A Florida program is offering free nicotine gum, lozenges and nicotine patches to help smokers "butt out." Call the Quit Line at 1-877-822-6669.

Traveling Tales

DOT Requires All Airlines to Accept POC Usage

Three years ago, the Department of Transportation (DOT) approved the use of five portable oxygen concentrators (POCs) during flight. The agency left it up to the airlines to decide if they would accept them or not. AirSep's LifeStyle and Freestyle, Inogen One, Sequal's Eclipse and Respironic's Evergo are allowed on most, but not all, airlines. Invacare's XPO2, which is also known as the Invacare Flyer, along with the two news POCs, Delphi's Life Choice and Superior Oxygen's Central Air, are awaiting FAA approval.

God bless the DOT who has amended its Air Carrier Access Act so oxygen users have the right to use the approved POCs on all airlines. They have made it mandatory that the airlines allow POC usage during flight, which includes domestic and foreign carriers who operate flights that begin or end in the United States.

Blaming insurance and safety issues, companies such as United, have refused to allow personal oxygen concentrators on board. The airlines who currently do not accept the oxygen units will have one year to comply with the new regulation. The DOT is seeking comments on the amendment.

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SeaPuffers pose on their way to a glass bottom boat tour of the beautiful scenery of Cabo San Lucas!

Product Corner

New POCs Coming on the Market

Two new portable oxygen concentrators (POCs) recently made their debut. When they become available to the public this summer, there will be a total of eight POCs available for the oxygen user's portable needs. FAA approval for use on the airlines is pending at this time for both models.

Superior Oxygen System's Life Choice weighs five pounds and has pulse settings of 1-3 only with a sleep mode that increases the sensitivity of the unit during sleep. At a pulse setting of 2, the internal battery lasts for 2 hours. The external battery adds more usage time, although we were unable to see how it fits onto the unit. For more information, visit www.superioro2.com or call 1-888-767-6994.

Central Air is now available and distributed by EVO Medical Solutions. This POC is made by Delphi, weighs ten pounds and can be carried by cart or carrying pack. The easy-to-change battery lasts about 3 hours at a setting of 2. It has a rotary compressor that operates at lower temperatures and has pulse dose settings from 1 through 5 at 0.5 increments. The cost will be approximately $3,800. To learn more, go to www.evomedical.com or call 1-800-759-3038 for information.

Not to be confused with Oxyview™ glasses, Ingen Technologies' OxyView® is an in-line oxygen flowmeter to measure the output from your gas or liquid oxygen equipment up to 4.5 LPM. It is put below your cannula to ensure accurate readings. The device is available from J and R Medical for approximately $20, which includes shipping. You may call 1-877-775-7633 to order.

NHOPA – the National Home Oxygen Patients Association – tells us of a product called Cord-A-Way that will wrap up to 8 feet of cord onto a small wheel. Designed for electrical cords, it might help eliminate the tangle of oxygen tubing around you too.

The product costs $17 and is available from www.shophometends.com (search for product #7116) or call 1-888-815-0814.

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Dedicated to Respiratory Health Care

Respiratory News

Cipla, a pharmaceutical company based in India, has introduced Triohale, the first triple combination inhaler. Triohale combines three medicines that are recommended for use in people with COPD. It contains a long-acting anticholinergic–Tiotropium (brand name Spiriva), a long-acting beta-2-agonist–Formoterol (Foradil) and an inhaled glucocorticoid–Ciclesonide (Alvesco or Omnaris) which is currently used to treat asthma and hay fever. Triohale is not available in the U.S. Visit the website, www.alldaychemist.com, for more information.

There may be fun in your future according to the *American Journal of Respiratory and Critical Care Medicine*. A computer game is being developed that uses your breath to play. Breathing techniques used during play just may reduce trapping in your lung and help you gain better control over your breathing!

The FDA has approved Advair Diskus 250/50 for the reduction of exacerbations (worsening of your COPD symptoms – coughing, shortness of breath, or coughing up excess mucus). The FDA also expanded the use of this strength of Advair for people with emphysema as well as those with chronic bronchitis. The FDA is also looking at the use of Symbicort for those with COPD. It currently is approved to reduce inflammation in those with asthma.

The Asthma Allergy Foundation of America has named Lexington, KY, as the worst city for allergy sufferers to live in the U.S., along with Greensboro, NC; Johnson City, TN; Augusta, GA and Jackson, MS. The five cities that should give allergy sufferers the least problems are Spokane, WA; San Francisco, CA; Bakersfield, CA; Sarasota, FL and Lancaster, PA. The American Lung Association notes that the Los Angeles area ranks as the most ozone/most particle polluted region of our country.

And just in case you hadn't already heard – annual flu vaccinations are highly effective at preventing respiratory illness. Official word comes from a study in a medical journal from the United Kingdom. Research showed getting the flu shot reduced overall problems by more than two-thirds.