



The Pulmonary Paper

November/December 2007

Dedicated to Respiratory Health Care

www.pulmonarypaper.org • Volume 18, Number 6



Learn about
the GOLD
Standards
for treatment
of COPD!

Also inside:

Calling Dr. Bauer
Sharing the Health

The Pulmonary Paper

News Magazine

Volume 18, No. 6

November/December 2007

On the cover: Matthew Vitanza recently enjoyed traveling with close friends and family.

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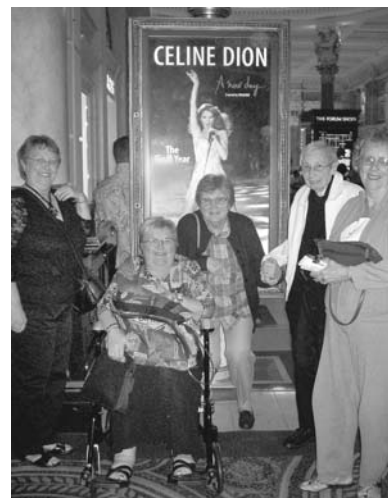
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As we cannot assume responsibility, please contact your physician before changing your treatment schedule.

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We saw Celine!

Hug your loved ones tight this holiday season and throughout the new year! Make new memories so you will always have them to enjoy!

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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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Raising parents is a difficult task and letting them go is even harder. The man on the front cover, Matthew Vitanza, was my *Pulmonary Paper* folder, taper and stuffer; my Dad; my gin rummy partner and my Santa Claus. Sometimes I was his caregiver and sometimes he was mine. When it came time to make difficult decisions, we did so in peace, knowing that in life, we made the most of the time God gave us. I thank you all for your continued and generous support.

The GOLD Standards

The Global Initiative for Chronic Obstructive Lung Disease (GOLD) recently updated clinical guidelines for the diagnosis, management and prevention of chronic obstructive pulmonary disease (COPD). The committee was made up of physicians and health professionals from all parts of the world.

According to their web site at www.goldcopd.org, COPD is now defined as a preventable and treatable disease. Worldwide, the most commonly encountered risk factor for COPD is cigarette smoking. A diagnosis of COPD should be considered in anyone who has difficulty breathing, chronic cough or sputum production, and/or a history of exposure to risk factors for the disease. The diagnosis should be confirmed by spirometry or pulmonary function testing. **Know your numbers!** FEV1 – or the amount of air you can forcibly exhale in one second – is used to classify the severity of your COPD.

The Committees Classified COPD in Stages

Stage I: Mild COPD

At this stage, the individual may not be aware that his or her lung function is abnormal. Smokers and ex-smokers, people over 40 years old and males have high rates of Mild COPD. Measured FEV1 (forced expiratory volume in one second) is greater than or equal to 80% of predicted value.

Stage II: Moderate COPD

This is the stage at which patients typically seek medical attention because of chronic respiratory symptoms or an exacerbation of their disease. FEV1 is less than 80% of predicted but greater or equal to 50% of predicted.

Stage III: Severe COPD

Greater shortness of breath, reduced exercise capacity, and repeated exacerbations which have an

impact on quality of life mark this stage. FEV1 is less than 50% of predicted but greater or equal to 30% of predicted.

Stage IV: Very Severe COPD

At this stage, quality of life is very appreciably impaired. FEV1 is less than 30% of predicted.

It is important to note that you should not become overly concerned if you have a low number. Many people live with less than 30% of their predicted FEV1 for many, many years. These standards are trying to establish a framework for the disease and do not take into account an individual's symptoms. The GOLD committees are trying to raise awareness of COPD.

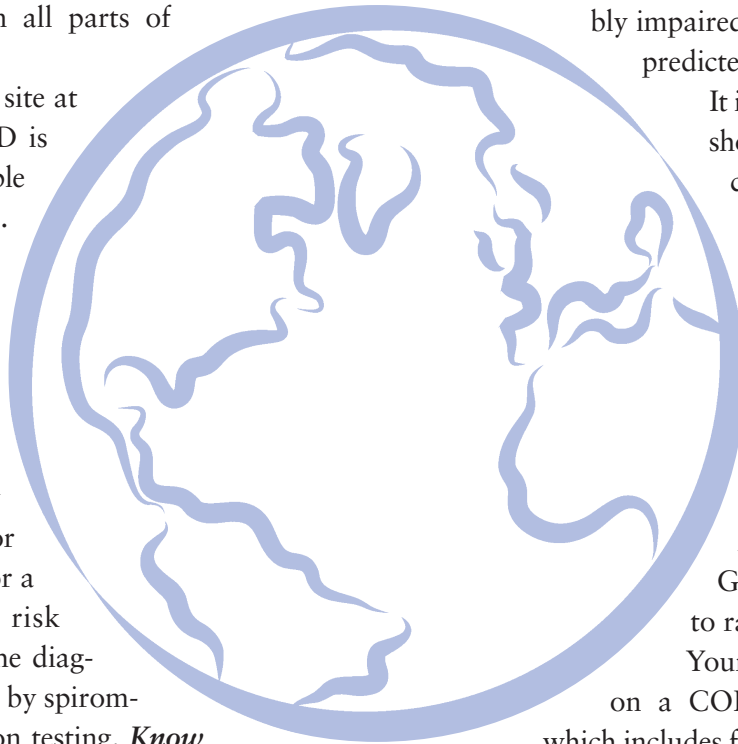
Your physician should have you on a COPD management program which includes four components: assess and monitor disease, reduce risk factors, manage stable COPD, and manage exacerbations.

Pharmacologic treatment can prevent and control symptoms, reduce the frequency and severity of exacerbations, improve health status, and improve exercise tolerance. You need to take your prescribed medication!

Patient education can help improve skills, ability to cope with illness, and health status. It is an effective way to accomplish smoking cessation, initiate discussions and understanding of advance directives and end-of-life issues, and improve responses to acute exacerbations. Get involved!

Resources

You will find many resources to spread the word about COPD from the National Heart, Blood and Lung Institute who has a campaign called Learn More, Breathe Better. To receive or download information call 1-301-592-8573 or visit their web site at www.nhlbi.nih.gov.



Calling Dr. Bauer ...



Dr. Michael Bauer

Dear Dr. Bauer,

I have emphysema and have been inhaling either Spiriva or Advair for about three years. I have just been diagnosed with glaucoma and can no longer take these inhalers. I also stopped my nasal spray. Could the inhalers have caused the glaucoma? Can I get any relief from some other inhaler or nasal spray?

Internet Elaine

All medications have side effects and, unfortunately, this is also true for your inhalers. On the good side, chances of serious side effects from most inhalers are *very small*.

The most common side effect of inhaled bronchodilators such as albuterol can be a rapid pulse rate or irregular heart beat. This is usually only a problem at high doses or with overuse. There have been some special concerns raised by the Federal Drug Administration (FDA) lately about Salmeterol, the long-acting bronchodilator component of Advair and Serevent. I believe most pulmonary specialists believe these medications are still very effective and may have an important role in optimal asthma/COPD treatment. They probably should not be the very first or only inhaler used to control breathing symptoms.

Inhaled steroids are the cornerstone of asthma treatment and may also be helpful in COPD patients. Most common side effects include a hoarse voice or yeast infection in the mouth. In general, the risk of serious side effects of inhaled steroids is *much less* than taking oral steroids. Risks of osteoporosis, glaucoma or cataracts are significant when taking long-term oral steroids, but are extremely low with usual doses of inhaled steroids. In most cases the benefits of this type of inhaler outweighs the small risks.

It's that time of year again. I would like to take this moment to thank all of our *Pulmonary Paper* readers for their support. Please share your knowledge about lung disease with friends. We all have a lot to offer each other. Best wishes for great times in 2008.

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@aol.com

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Fibrosis File

Pulmonary Fibrosis has been in the news recently. Ironically, we just lost death-defying Evel Knievel and also singer Robert Goulet to the disease.

Dr. Steven Idell of Tyler, TX, has discovered an enzyme that carefully eliminates scar tissue and blood clots that inhibit lung function. It's called single-chain urokinase plasminogen activator, or scuPA. Idell said scuPA doesn't act like other agents. It doesn't eat everything away, but instead is slow-acting and only reacts with tissue it is meant to destroy. Inhaling scuPA could be a potential treatment for pulmonary fibrosis. Dr. Idell is applying for clinical trials to be conducted by the National Institute of Health.

The *Journal of Clinical Investigation* reports "Telomerase, a protein most notable for its connections to aging and cancer, has been shown to have increased activity in mice with lung fibrosis. University of Michigan researchers have identified telomerase in the progression of pulmonary fibrosis. Telomerase activity is dependent on the presence of a related protein named TERT. The study found that mice with reduced TERT



Robert Craig
"Evel" Knievel

levels also had reduced telomerase activity in the lungs, and less severe lung fibrosis. This effect was reversed if the TERT-deficient mice were transplanted with TERT-sufficient bone marrow cells prior to lung injury."

CoprexTM is an oral, anti-copper agent that is highly specific for the reduction of free copper in blood serum. Pipex Pharmaceuticals is developing CoprexTM for fibrotic disorders based upon the rationale that the fibrotic disease process is dependent upon the availability of free copper in the body. CoprexTM has demonstrated the ability to inhibit fibrosis in a number of animal trials. The company is planning to initiate a phase III clinical trials.

Better Breather Speaker Topics: Keep It Lively!

Are you starting a new group or scheduling speakers for your Better Breather Club meetings for 2008? Janie Severns of Coarsegold, CA, has suggestions of people to keep your sessions interesting and lively!

Ask a Pulmonologist or Respiratory Therapist to speak on How the Heart and Lungs Work Together or Asthma and COPD Medicine and Management Programs. A Physical Therapist will teach you Better Breathing through Exercise, Chair Exercises for COPD or ask a Yoga Instructor to visit. A Home Health Nurse, Registered Dietician, Oxygen Supplier, Psychologist, Occupational Therapist and Emergency Medical Personnel are all full of valuable information. Your own members may share travel experiences and other tips. With just a little planning, you will be on top of your COPD!

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Ask Mark ...



Mark Mangus, RRT
EFFORTS Board

Chris from EFFORTS asks if an oxygen saturation level below 94% will cause permanent damage to the body's organs.

Mark replies: There is no evidence that a sustained saturation of 93% will significantly affect brain function or judgment. While at 88% things may start to get a little fuzzy for some, it is the “sustained” desaturation that is damaging to the brain and organs. We have many examples of people, whose oxygen saturation hovered in the low 80s and upper 70s for days during episodes of Adult Respiratory Distress Syndrome, who completely recovered with most, if not all their mental faculties intact. We can tolerate short-term drops in saturation without sustaining any significant injury. The “hard” number below which we see reproducible and frequent injury occur is “sustained” desaturation below 85%. Sustained means for a period of days and without significant rise in saturation during that time.

Comfort and performance of physical activities is another matter altogether. They do indeed suffer when saturation drops below 95% and more so, the lower it goes.

Kelly also wondered about permanent lung damage if you have an exacerbation.

Mark writes: Exacerbations are “flare-ups” of your COPD symptoms and can be caused by anything from inflammation to infections with viruses and or bacteria. The length, severity and ‘process’ of a given exacerbation may range from no permanent changes to severe and permanent damage that pushes a person into the next level of disease severity. We cannot simply categorize expectations and say what changes will occur for certain.

The best we might say is that what you as an individual make of your situation and its obstacles determines how you will do over time. I will talk incessantly about keeping moving and exercise and working “within” your discomfort and breathlessness to eventually push it back to where it doesn’t have such a powerful effect on you. We cannot overemphasize enough the fact that it is all dependent upon what you can tolerate towards regaining and increasing strength and function and achieving the best state of health and stability that you can. If you expend too much energy fretting about every little change and trying to analyze and categorize every detail of your disease, you’ll likely miss the most important details that have bearing upon living with COPD! Your attitude is critical in that quest!”

Myra writes: I have COPD and am on transtracheal oxygen. I noticed I become short of breath while trying to do chores, as using a vacuum wand.

Mark replies: I would start by asking you to review your level of activity and see if much, if not most, of your difficulty stems from simply

being ‘out of shape’? Getting up and moving – especially doing tasks that require upper body exertion – takes those muscles away from helping with breathing and results in rapid onset of windedness. We then tend to do less and stop sooner. Over time, we find we cannot do what we could only a short time ago and the spiral continues until we can hardly function at all.

Exercises to strengthen your upper body are in order, but you need both resistance exercises for strengthening and aerobic exercises for endurance. Arm biking and weight training for your upper extremities is in order. Walking and/or leg biking is necessary for your legs as well as step and leg resistance training exercises.

The greatest challenge you have is to resist stopping or slowing down when you ‘achieve’ windedness. Most folks make the mistake of thinking they should not get winded and have to work hard to breathe. The goal of exercise is to challenge your breathing, to get winded and to continue to work ‘within’ that windedness to achieve and maintain control of anxiety, panic and breathlessness with rhythmic and pursed-lip breathing. Folks who cannot do this will progress only modestly and very slowly. So, push as hard as you can. Breathe as hard as you can. Best Wishes!

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) who 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 was told that I had at about two years to live with my severe emphysema. I am into my seventh year, struggling, but I refuse to give in. There are many things that I can no longer accomplish, but I like to focus on what I can do and be very grateful for being able to think right!

LG, North Vancouver, Canada



When I first went on oxygen, I found out I needed a lung transplant. I am still waiting but have a new outlook on life, thanks to the pulmonary rehabilitation staff at McLaren Medical Center. I go three times a week to walk a mile on the treadmill and use the machines. I ride my Honda scooter all around town and just strap my oxygen around my waist and away I go! I thank God for my family and friends who keep me going!

Linda MacLaren, Otisville, MI

I am a COPD patient. I never smoked. Every time I meet a new nurse or doctor, most assume I smoke or did smoke. What a downer! No one deserves to get COPD – smoker or non-smoker. I am thankful for a supportive family and doctors and nurses who help me. Jesus and my church support me through the hard days.

CA, Bedford, IN

I can manage being one-on-one with people but with more than one, I feel like I am competing for oxygen, trying to talk. It really bothers me not to be able to converse, discuss or talk on the phone. I feel like a moron, which greatly increases my emotional stress and isolates me. The whole oxygen scene makes me feel undervalued. I'm glad and grateful to be alive though!

AR, Santa Maria, CA

When I first got on oxygen, I lit up a cigarette and burnt my face up and almost my house. I quit the next day. I thank God for this, life is much better. Smile and laugh, it's good for you!

DH, Sea Hunt, CA

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Sharing the Health

A Poem

*There was an old lady
who lived in the woods.
I feel fine, she did say
as long as I have my baked goods.
Except for the fact
that I've been sacked
with a hose up my nose,
that's just the way life goes.*

Judith Stuart, Antrim, NH

I found this tip in my local FOCUS Community Newspaper: My husband and I were on vacation. Since most rental places do not rent smoke-free cars, we had to come up with something fast to get the cigarette smoke out of the car. We went to the grocery store and bought a potato, sliced it in half, and put one half in the front seat and one half in the back seat. The next day the smoke smell was virtually gone.

Lori Palermo, Gouldsboro, PA

If you are wondering what to get that special someone on your Christmas list, you might visit www.rehabilitystores.com on the internet. Unfortunately, they do not have a printed catalogue at this time. They stock unique items such as slippers with lights that sense darkness and automatically turn on and aqua belts to help you exercise in the water.

I have written to elected officials to ask for support of the Home Oxygen Patient Protection Act, HR 621 and S1484 which would repeal the Deficit Reduction Act calling for Medicare beneficiaries to take over ownership of their oxygen concentrators after 36 months of use. I believe it should also mandate that new equipment be provided if the new regulation does go into effect on January 1, 2009.

When I called to ask for new equipment before the concentrator ownership is transferred to me, I was told they would send newer equipment. When I asked again, they said Medicare does not require them to provide new equipment. When I asked again, they said

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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.

they would try to place an order. I called back to tell them I had found another equipment supplier who would provide new equipment and service. I would like to advise your readers to work with their medical supply company to get new equipment before the new rules go into effect.

Steve Ganshert, Sartell, MN

I recently saw a doctor on the news talking about the Neti Cleansing Pot by Ancient Secret. This is a nasal cleansing method which he said was the best thing to use if you have sinus/allergies problems. You can find the Neti Pot on the internet or at local health stores at a cost of approximately \$15.

GrayG114

I tried tubing from www.softhose.com (1-858-748-5677) and cannot use any other cannulas or tubing anymore. They are the softest and lightest ones I have ever used. To help from getting tangled up, I just pick my tubing up and coil it around my wrist as I walk around the house. This prevents it from catching on the corners of coffee tables, doors and whatever tubing can find to get caught on. It is a pain but something we have to live with I guess. Best wishes to all.

Mary Ellen Oliver, Fontana, CA

I have been on oxygen for the last few years. Try getting colored tubing so that it stands out more than the clear tubing. You can even use RIT dye to pick your own tubing color!

Rada Beth Maples

I was looking for help when I was trying to give up cigarettes for good. I found a web site called www.whyquit.com which was very helpful with personal stories. It has many tips for people who are trying to stop "cold turkey." They also have a phone you may contact founder John Pilito of South Carolina at (843) 849-9721.

Marie Mynatt, Knoxville, TN

Mary Rhoades of Leesburg, FL has had this poem for a very long time. She would like to share it with you!

My Name Is I Am

*I was regretting the past
and fearing the future,
Suddenly my Lord was speaking;*

*“My name is I AM,” He paused,
I waited, He continued,
“When you live in the past
with its mistakes and regrets,
it is hard. I am not there.
My name is not I WAS.”*

*“When you live in the future
with its problems and fears,
it is hard, I am not there,
My name is not I WILL BE.”*

*“When you live in the moment,
it is not hard. I am here.
My name is I AM.”*

That's Ron Wilson from Tulsa, Oklahoma, on the dance floor dancing, like nobody's watching! What an inspiration to watch Ron dancing for and in celebration of life. Ron became ill with emphysema five years before he began using oxygen. He was not eligible for a lung transplant until the 65-year-age limit was raised to 70 years. He was on the transplant list for 32 months before receiving a double lung transplant in St Louis. Fortunately, he was called within 31 days of his move, and received a double lung transplant. He now takes 17 different medications and will so for the remainder of his life. He's now without his oxygen tank and appreciating each precious breath of air. What a joy it is to see him



on that dance floor with or without a partner, making up for all his lost time when he was limited in what he could do. Please pass the word about the importance of being an organ donor! Aline Wisher, Bixby, OK

I was wondering if others have a burning smell that sometimes comes from your oxygen concentrator. I have called my company and they have checked and said everything seems ok. One time the concentrator just quit, never to start again. After replacing it, the new one started to smell and they replaced it again. They suggested I keep a fan going on the concentrator itself.

Has anyone heard of this problem before? I would appreciate any suggestions or information our readers may have. I do check the filters and wash them weekly, change the cannula every couple weeks and the large hose once a month. Glenna Miller, Fayetteville, NC

I may have stumbled onto something that might be of interest to the readership. For several months now, I have been phasing in and out of a stubborn, and discomforting, urinary tract infection. My urologist identified it as a fungal (yeast) infection, and has treated it with an anti-fungal medication, which clears it up for a while, but after a few weeks it is back. I've now had three or four episodes.

About two weeks ago, I saw a television ad for Spiriva, and they mentioned that one of the possible side-effects of the drug was urinary difficulties. I contacted Boeringer Ingelheim, the manufacturer, and they confirmed that Spiriva might be the cause of my problem. I am hoping there is another pill I can take to counteract this as I don't want to give up my Spiriva!

Ken Carter, San Antonio, TX

A Lithuanian Grandma's Chicken Soup

- (1) 5- to 6-pound stewing hen or baking chicken
- 1 package of chicken wings
- 3 large onions
- 1 large sweet potato
- 3 parsnips
- 2 turnips
- 11 to 12 large carrots
- 5 to 6 celery stems
- 1 bunch of parsley

Place cleaned chicken in a large pot and cover with cold water. Bring the water to boil. Add the chicken wings, onions, sweet potato, parsnips, turnips and carrots. Boil



about 1-1/2 hours. Remove fat from the surface as it accumulates. Add the parsley and celery. Cook the mixture about 45 minutes longer. Remove the chicken. The chicken is not used further for the soup. Put the vegetables in a food processor until they are chopped fine or pass through a strainer. Season with salt and pepper to taste.

We hope you have received your flu shot to protect you this winter season. Good old chicken soup may also help! A University of Nebraska Medical Center researcher used his Grandma's recipe to test its medical value in a study published in CHEST seven years ago. Chicken soup may act as an anti-inflammatory that could help with respiratory infections.

Traveling Tales

SeaPuffers Visit Grand Canyon and More!

A group of oxygen users and their friends made it through the desert and over dirt roads to walk on the new Skywalk over the Grand Canyon. As they posed for a group picture with their portable oxygen concentrators and tanks, they noticed a man smiling who came over to say, "Way to go guys!" The man turned out to be a physician, a lung specialist, who was on vacation and wanted us to know we made him very proud!

It was not all play on this recent SeaPuffer trip. We were treated to a lecture on transtracheal oxygen by respiratory therapist extraordinaire, John Goodman, and Mark Mangus, himself was on hand to answer questions about living with chronic lung disease. Sean Gillespie from OxyView Glasses demonstrated how to hide your oxygen tubing from view and Lori Palermo brought her message of COPD awareness in honor of her father, Wayne A. Litzenberger. *See sidebar below for more information.*

Learning about lung disease, while traveling with old and new friends, is an unbeatable combination. Respiratory Therapists will be helping travelers leaving from Fort Lauderdale, San Diego, Seattle and New Jersey in 2008. For information on upcoming SeaPuffers Cruises and Travel, call Pam at 1-877-473-2726 or visit www.seapuffers.com.

Spread the Awareness of COPD!

Lori Palermo maintains a web site at www.loveyourlungs.com and has designed two lapel pins to raise public awareness of COPD. Each pin may be purchased for \$3 which includes shipping and handling.

You can send for the pins by writing Lori at RR 1, Box 1220, Gouldsboro, PA 18424.



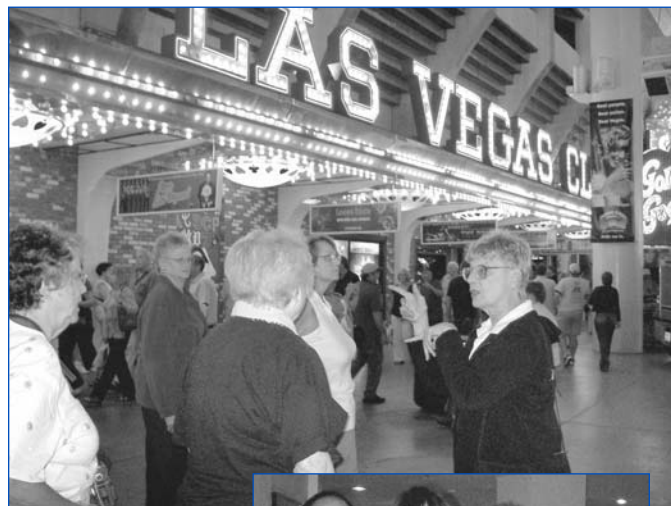
COPD Awareness



Smokefree Living

Bob Zimmerman of Pitman, NJ, wants to advise those who will be renting a portable oxygen concentrator (POC) for travel use to try the unit a full day before leaving home in case something goes wrong and the unit needs to be exchanged. When driving, Bob brings a portable tank for emergency use.

The new XPO2 POC from Invacare has been submitted to the FAA for approval for use on the airlines. For more information on oxygen use during airline travel, visit www.airlinecouncil.org or call the COPD information line at 1-866-316-2673.

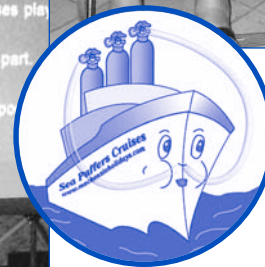


Above: Hittin' that Vegas Strip, Baby!

Right: Suzie Bulwan and family enjoy a photo op moment.



Below: Respiratory Therapist Mark Mangus addresses COPD.



Product Corner

New Oxygen System Coming Soon

A new type of oxygen system will soon be available from Inspired Technologies.

Called the VIAspire™ personal oxygen system, it involves a concentrator that feeds into a larger reservoir to produce liquid oxygen in the home. You will fill your liquid portable from the reservoir. A unique feature of the portable units, which are available in three sizes, is SmartDose™ technology. The portable will automatically vary the oxygen flow rate it delivers as it senses an increase in your breathing pattern. The company claims the portable is quiet and will last up to 16 hours – giving you freedom to move about the house and away from home.

The VIAspire™ has been approved by the FDA and is scheduled to be available in March of 2008. Information may be seen at www.inspiredtechnologiesinc.com or call the company in Pennsylvania at 1-724-861-5510.

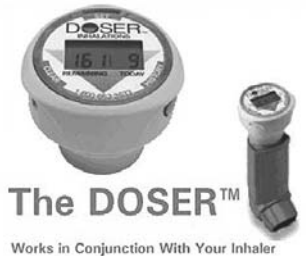


Dose Integrated Delivery System Arrives

3M has developed a dose by dose integrated delivery system that will be used with metered dose inhalers.

Ventolin HFA, an albuterol inhaler from GlaxoSmithKline, is using the new counter. (HFA is an inhaler without chlorofluorocarbons which are thought to harm the earth's ozone layer.)

A similar product, the Doser from Meditrack, has been available for a number of years – it is used to count the doses left in your inhaler. A warning signal is given when there are 20 doses left in the canister. You may call 1-800-863-9633 or visit www.doser.com for more information.



Works in Conjunction With Your Inhaler

The Eclipse, the portable oxygen concentrator with continuous flow from Sequal, has new accessories that may make life a little easier for you. The company recently introduced a desktop battery charger, an improved cart with larger wheels, an adapter to add humidification and a carrying bag for the back of wheelchairs and scooters.



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Respiratory News

The Spanish pharmaceutical company, Almirall, is developing an inhaled dry powder medication for those with COPD they call acclidinium bromide. Brand names will be Eklira®/Bretaris®. They claim the drug will provide faster, longer-lasting bronchodilation with fewer side effects and will be easy to use. Phase III clinical trials are now underway.

Researchers from the University of Virginia School of Medicine have identified structural damage to the lungs caused by second hand smoke. Thanks to sophisticated radiology equipment, this is the first time the detrimental effects of second hand smoke could be documented.

Many of you now use Foradil® (formoterol fumarate), a dry powdered inhaler from Schering Corporation. The same drug is now available from Dey Pharmaceuticals as a solution to be used in a nebulizer. The company calls this new form of the drug, Perforomist™. Formoterol is a long-acting bronchodilator, taken twice daily, for those with emphysema and chronic bronchitis.

As an alternative to Lung Volume Reduction Surgery, several companies have been developing stents or valves that are placed in your airway during bronchoscopy to decrease the hyperinflated sections of your lung.

Emphyasys Medical manufactures a one-way endobronchial valve. Researchers from the University of Pittsburgh found the valve gave those with emphysema significantly improved measures of lung function who then reported a better quality of life.

Broncus Technologies, Inc. found a significant reduction in the amount of air trapped in the lungs of people who had their ExhaleRStent placed. During the minimally invasive procedure, new openings are created in the airway wall, connecting the damaged lung tissue to the natural airway. These pathways are supported and kept open by the stents. For information on participating in their clinical trials, call 866-431-3273 or visit www.EASEtrialUS.com.

Spiration, Inc is also recruiting people for their IBV Valve Trial. Visit www.emphysematrial.com or call 1-877-547-8839 to see if you qualify to participate in the study.