The Pulmonary Paper

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Dedicated to Respiratory Health Care

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Travel with Jeri (Look closely, she is using oxygen!)

Also inside:

Home Oxygen Patient Protection Act

Calling Dr. Bauer

New Products

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On the cover: Jeri Mondloch of St. Peter, MN, does not let lung disease keep her down!

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contents

Marilyn Ristau
of Middleburgh Heights, OH

Call your local American Lung Association office or check on the Internet for a flu clinic nearest you by visiting www.flucliniclocator.org

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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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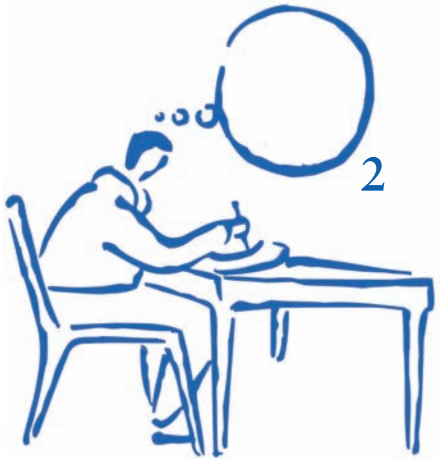
Next year marks our 20th year of publishing *The Pulmonary Paper* and we thought our newsletter needed a little updating. We hope you like the new format and we welcome your comments.

The one thing that will never change is our nagging you to get your annual flu vaccination. Don't be one of the 36,000 people who do not survive complications from the flu this season. We care too much about you!

Celeste

You can make a difference!

Presently, the Deficit Reduction Act calls for Medicare beneficiaries to take over ownership of their oxygen concentrators after 36 months of rental. It is then up to the oxygen user to determine if their equipment is working properly. This leaves many unanswered questions as to travel needs, emergency equipment and service. If you were using a concentrator from a home care supplier on January 1, 2006, you will automatically own it on January 1, 2009. Some lawmakers would like to reduce the rental time from 36 months to 18 months!



The Home Oxygen Patient Protection Act, HR 621 (House version) and S 1484 (Senate version) are identical bills. The House and the Senate are discussing the same issues. HR 621 and S 1484 call for rescinding the 36-month concentrator rule and return Medicare payments for oxygen to where they were before the Deficit Reduction Act was passed. There is so much more to oxygen therapy than paying for a concentrator.

In September, lawmakers returned to Washington, DC. You can call (1-202-224-3121), email (find a link to your senator at www.senate.gov) or visit both Senators from your state, and ask them to support HR 621 and S 1484. Mailing a letter may take too much time!

Identify yourself to the senators, letting them know you are a supplemental oxygen user. Tell them the House of Representatives has passed HR 3162, which would reduce oxygen payments and may eliminate your choices of portable oxygen systems. Ask that they support the Home Oxygen Patient Protection Act HR 621 and S 1484 to repeal oxygen concentrator transfer of ownership.

A government study found that people who use home oxygen are less likely to go to the hospital. Home oxygen costs Medicare $7.62 per day; one day in the hospital can cost as much as $4,600. More than one million people on Medicare use oxygen.

John Grub of Enola, PA, learned about the Home Oxygen Patient Protection Act and immediately wrote his elected officials. He also contacted 30 of his friends and relatives, asking them to contact their local senators for support.

Jim Ryan of Honeoye Falls, NY, reports, "The panic among oxygen suppliers has already started. My supplier called to inform me they will no longer be handling liquid oxygen because they don't see any profit in it. They said I will have to switch to cylinders or find another liquid supplier. The problem for me is I have tried numerous conservers in my seven years of oxygen use and find none keeps me saturated except for the Caire Spirit 300, which is a liquid system."

Anne Glasner of Wisconsin, wrote to her Senator, Russell Feingold. He wrote that he would keep her thoughts in mind.

We contacted Wayne Knewasser, Vice President Public Relations/ Government Affairs of Premier Home Care Inc. in Louisville, KY, and president of Kentucky Medical Equipment Suppliers Association.

Wayne asks our members, "How many of you have taken the time to make the call to your elected officials? If you can answer 'I did', you did a great service to yourself and the COPD community."

"Homecare, which accounts for approximately 3 percent of the total Medicare budget, continues to experience cuts in benefits and services as seen with the Deficit Reduction Act. Why is it then, that the most cost-effective means of providing healthcare services to an aging population, continues to experience Medicare cut backs? Is it possible that our Congressional leaders do not understand the cost effectiveness of providing in-home care? Or is it because we are a minority population and do not speak out with a strong voice as a consumer, family member or business owner?"

Wayne continues, "Continuous rental of oxygen concentrators has drawn considerable attention from the Office of the Inspector General (OIG) and the Centers for Medicare and Medicaid Services (CMS). The contention is that the monthly allowable for the rental of the concentrator is their basis for determining reasonable reimbursement for in-home oxygen services. There is no existing means to determine the costs associated with

continued on page 5

Calling Dr. Bauer …

Dr. Michael Bauer

Dear Dr. Bauer,

I am wondering why my physician has not prescribed oxygen when I have such a hard time breathing!

Sincerely, Sharon O'Brien of Colorado

Many of my patients with lung disease ask "How can I be so short of breath, when my oxygen levels are still OK?"

For those with emphysema or COPD, the normal elastic tissues in the bronchial passages and lung are reduced dramatically. Cigarette smoke alters the enzyme levels in the lung and results in lung destruction. Since the bronchial passages are so "floppy and loose," they collapse very easily while exhaling. This premature collapse of the lung passages can result in shortness of breath even if oxygen levels are not very low. Pursed lip breathing works so well for patients with lung disease because it tends to keep the airways open longer while exhaling.

Those with lung disease due to fibrosis or interstitial disease have thickened, stiff bronchial and lung tissue. This is almost the opposite of emphysema, yet shortness of breath is a common denominator. Since the lungs are so stiff with fibrosis, the muscles of breathing need to go into overdrive to get air in and out. This results in sensations of shortness of breath.

I hope these explanations are helpful for you.

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

Pursed lip breathing works so well for patients with lung disease because it tends to keep the airways open longer while exhaling.

continued from page 3

providing patient care and services to the oxygen beneficiary. The OIG has stated they have reviewed the cost of providing in-home oxygen services based on equipment purchase price versus the length of the rental. Costs associated with providing services were largely ignored. Until there is a significant change in the way they perceive in-home oxygen, you can expect to receive further reductions.

The main issue, as I (your in-home equipment provider) see it, is we as a group (equipment suppliers) have not been united in educating our beneficiaries and legislators about the advantages of providing in-home oxygen. You come first!

To achieve results, requires a serious commitment on the part of the provider and the beneficiary to be as informed and actively involved with every aspect of the needs to the COPD population we serve. It requires developing and implementing educational programs and participating in support groups."

We agree with Wayne, we all need to be actively involved.

Fibrosis File

The Coalition for Pulmonary Fibrosis (www.coalitionforpf.org, 1-888-222-8541) recently sponsored the fifth annual National Idiopathic Pulmonary Fibrosis (IPF) Awareness Week. Nearly 50 advocates, many of whom were patients and family members, took part in meetings on Capitol Hill and urged Congress to increase federal funding for IPF research in the Fiscal Year 2009 budget cycle. The group urged passage of legislation important to the IPF community, including a resolution specifically calling for IPF research and ending the Medicare Disability waiting period for patients with life-threatening diseases.

IPF has touched the lives of Ruth and Ray Conroy of Brookfield, CT. Ruth has had emphysema and IPF for the last 25 years. They have done all the right things, flu shots every year; pneumonia vaccine every 5 years; pulmonary rehabilitation and oxygen therapy.

Ray thinks they have been fortunate and have had few problems over the years. He writes, "With the advent of new diagnostic ability, the prevalence of IPF is growing. The need for advocacy for the patients has grown proportionally. We have been married for 60 great years and the journey we are presently on is tough. I have learned a great deal about my wife's care and am now working with the Coalition for Pulmonary Fibrosis to start a support group as there are none in the state of Connecticut. In many ways, IPF mimics COPD but my mantra is 'IPF is not COPD!' Having our family around us helping and with the help of our higher power, we are making the journey together and are living every day to the fullest."

Earlier this year, Dr. Richard Gomer of Rice University discovered a naturally occurring blood protein that prevents scar tissue from forming. The protein, which is called serum amyloid P, or SAP, has proven effective at preventing fibrotic disease from developing in the hearts and lungs of lab animals. For information on IPF clinical trials that are currently recruiting patients, visit the CPF website.

Below: Supporters of the Coalition for Pulmonary Fibrosis strike a pose during their recent IPF Awareness meeting in Washington, DC.

Ask Mark …

Mark Mangus, RRT
EFFORTS Board

EFFORTS member, Meryl, recently asked Mark about anesthesia for COPD people. Her recent pulmonary function test revealed an FEV_1 (Forced Expiratory Volume in one second) of 25% to 30% of normal.

Mark replies: "While a FEV_1 25% to 30% is low in terms of FEV_1, it does not automatically prevent you from having anesthesia. Taking chances on frivolous or primarily elective surgeries is not the thing to do and you likely won't find an anesthesiologist to put you to sleep for such things. Surgeries to correct problems that affect function or daily life must be weighed against the potential combination of COPD and anesthesia effects.

I've had many patients who were immobilized by degenerative joint disease. Their pulmonologists forbade them to go under the knife for fear of "getting stuck on a ventilator" afterwards. Some have heeded their doctor's command against surgery/anesthesia and continued to deteriorate. Those who went ahead with the surgery, for the most part, did just fine. Few, out of many hundreds, actually ended up in trouble as the result.

My recommendation is always check with the anesthesiologist. Realize that no anesthesiologist is going to risk putting you under, if there is a reasonable chance you'll have difficulties. If the anesthesiologist feels confident that he/she can get you through surgery without long term ventilation (barring unpredictable complications, of course), then go for it.

Ralph from Arizona asks, I have been advised to wait at least a minute or longer between taking Foradil and Spiriva. If I take them together, would they cancel each other out?

Mark replies: These are two different drugs that do two different things. Foradil is taken twice a day and is a long acting beta2-agonist medication while Spiriva is a once-a-day anticholenergic bronchodilator. They are both indicated for the long-term maintenance treatment of COPD.

They do not have any affect upon each other. They can not 'cancel' one another. There are versions of combinations of Spiriva and long-acting beta2-agonists in clinical trials right at this moment. I expect that soon we'll have a new drug that is a combination of the two on the market.

Those taking Spiriva and Advair need not wait to take Spiriva until your Advair has had a chance to work. There's no advantage in doing so. You can take them both together without influence of one to the other.

Ken from California wonders if an oxygen saturation reading of 90% would be adequate.

Mark replies: If a person is at rest, breathing room air, a saturation of 90%, is adequate and safe, although not ideal and not comfortable for everyone. If 90% is the highest you can get while you are walking around, it is most likely safe also. I think we all agree that those who can not maintain at least 90% are going to suffer over time. There is a lot of evidence, under various conditions, that a saturation of 90% is sufficient for the bulk of the population to sustain, without invoking injury. Saturations above 90 % increase the "comfort factor."

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 wish I didn't have COPD. I wish I wouldn't run out of breath when I walk outside to see my wife's garden. I wish I could go to the tourist places and see the pretty sights. I wish I could eat a hearty meal. I wish I could take a stroll down the street in the evening. I wish we could go dancing again. But I have COPD and it's most likely my fault for not taking better care of my lungs. BUT, I love it that I can read a good book. I love it when my loved ones come to visit. I love the taste of good food. I love it when my wife drives me around in the Fall to see the pretty colors. I love it when my grandchildren say "I love you Papa and hug me". I love it that my loved ones still treat me like with respect and kindness and not like "the old guy that can't breathe," and that every one of them tries to take care of me and sees to my comfort. Ain't this a great world the Lord has given us! Thank you Pulmonary Paper and all the contributors for bringing this information and forum to us. It's invaluable to me.

GW, Pensacola, FL

My beautiful mother, Margaret Boggs Davis, was diagnosed with COPD in 1991. The day she entered the hospital and was put on a ventilator would change our lives forever. She enjoyed traveling to the beach and mountains in North Carolina, even when she was put on oxygen 24/7. It wasn't long after 1998, she started subscribing to The Pulmonary Paper. This newsletter alone provided so many outlets to my Mom and our family. I want your readers to know two very important items that were advertised, that if not for them, my mother would not have had the quality of life she did.

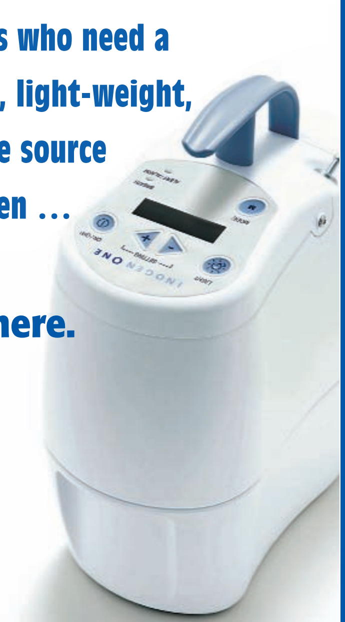
First was her trusty Nonin Pulse Oximeter. She was so excited to learn that she could test herself to see when she needed to slow down or needed to go to her doctor if her SATs remained too low. Second, was her beautiful rose-colored Oxy-View glasses. She lit up the room with her smile because she felt confident that no one was staring at her cannula. Those two items made my Mom's life so much easier. I cannot stress to your readers to purchase those two items for themselves or a loved one.

Grief is a reminder that we once loved and we were loved in return. A special thank you to all the members who submitted articles over the years that provided words of comfort and advice to our Mom.

Holly Davis and family, Trinity, SC

Living with COPD means not being able to golf for the past three years, wearing oxygen in the shower, constantly filling tanks and not even wanting to shop! COPD stinks! That's how I feel.

BC, Lawrence, MA



Poetry Corner

I was adjusting to being on O_2 and had trouble learning how to attach and detach the conserving device to my portable tanks. My daughter knew I like poems, so she wrote the directions in verse. Now I'm doing just fine!

Conserving device …
Green key-silver dome
This is how I'll start my poem.
Turn the key clockwise to close,
Stops the oxygen to my nose.
Now gray handle on the side
Must be loosened–device will slide
Off of the tank, allowing me
To put in new tank easily.
The tricky part in all of this:
Aligning prongs–I must not miss.
Once prongs are in (they're like a plug)
Turn gray handle until snug.
Now with green key one-half turn
Counter-clockwise I did learn.
Make sure O_2 *is set at three*
Now I'm ready–Now I'm free!

by Heather Ver Brugge for Eleanor Hoppe
Albuquerque, NM

I have a neurological problem which keeps my COPD company. My feelings about them came together in this poem.

Sometimes as I sit …
In cold October gray
I wonder why the man
Is treating me this way.
It seems I'm always sitting
In the freezing rain,
Wet, cold and wondering
"Why must I sit in pain?"
Then I begin to realize
The storm is just a door
Opening up my heart
For the sun to shine some more.
Warming me with the laughter
Of my children through the years,
Knowing love in the fingers
That brush away my tears.
A chance to savor each moment
That has been and is still to be
A chance to know the joy
That life has meant to me.

by Mike Womack
Budd Lake, NJ

Traveling Tales

Some Airlines Not Helpful to Oxygen Users

Jeri Mondloch of Minnesota is a frequent traveler despite being on oxygen. She has tried every form of oxygen known to man and flown on many, many airlines. Despite her small stature, she has scrapped with airline attendants, pilots and representatives about her portable oxygen concentrator and has always won. (She uses the Eclipse with continuous flow so she may use it with her CPAP equipment at night.)

Jeri wants to warn her fellow oxygen users that Delta Airlines is not making it easy for them. She found if you want to use one of the approved POCs, you have to fill out a physician's statement, which includes general information completed by the passenger and a section completed by the physician. It is then faxed to Pittsburgh Medical Center (a minimum 48 hours prior to departure.) Jeri says, "You pay $25 to have the above forms reviewed and then will be notified if you can fly or not! You do not get the $25 back if they flunk you! What will they think of next to make it even more difficult for oxygen passengers!" Tom from California called to report Alaska Airlines has begun to charge $50 for POC screening!

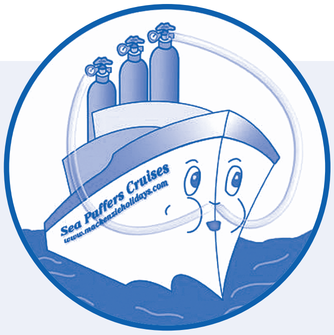
If you would like to find out what airlines will allow you to fly with your POC, check with the manufacturers' web site or call the company. Be sure to know the airline's specific regulations – we recommend printing them out and having them with you, along with your oxygen prescription, when you board.

LifeStyle and FreeStyle POCs from AirSep Corporation
www.airsep.com
1-800- 638-2041

Eclipse from Sequal Corporation
www.sequal.com
1-(800) 826-4610

Inogen One from Inogen
www.inogen.net
1-877-446-6436

EverGo from Respironics
evergo.respironics.com
1-800-345-6443



SeaPuffers, Ahoy!

So you're ready to travel? Join the SeaPuffers for new adventures in 2008! Respiratory Therapists will be along to make sure all the oxygen and mobility equipment is where it should be. You will learn a few tips and try out new equipment along the way.

- **Panama Canal Cruise**

  The Panama Canal is always a favorite among SeaPuffers as they enjoy the fascination of cruising through the canal as well as relaxing and enjoying the ports of the Caribbean. This trip leaves from Fort Lauderdale on February 11 and returns on February 21, on Holland America's *ms Volendam*. Just in time for Valentine's Day!

- **Mexican Rivera and Sea of Cortez Cruise**

  This ten-day cruise leaves from San Diego on March 16, 2008, on Holland America's *msRyndam* to see Puerto Vallarta, Cabo San Lucas and other exciting port cities. You will enjoy the incredible beauty of the country … but the last time the SeaPuffers were on this cruise, we had to monitor the tequila tasting! Celebrate St. Patrick's Day!

- **Alaskan Cruise**

  Fire up this Fourth of July on this seven-day cruise to Alaska from Seattle on July 4, 2008!

For information on SeaPuffers Cruises and Travel, call Pam at 1-877-473-2726.

Herb and Coralee Hansen of Hopkinton, NH, enjoy themselves on a recent cruise.

Sharing the Health

For those of you who have access to the Internet, try visiting www.youtube.com and searching for COPD. There are several videos to watch – you might even want to try making one of your own to share with others!

To save battery life when using a portable oxygen concentrator, travelers are advised to plug into the airport's electrical outlets. But with so many laptop computer users, an empty plug may be hard to find. Jack Oliver of Illinois came up with a very simple solution. Pack a multiple outlet adapter or strip with your POC equipment and you are sure to find someone who is willing to share the electricity!

When Mary Jane Gormley travels, she finds hotel rooms often do not have enough surface space to hold her respiratory supplies. Mary Jane recommends using the ironing board as a spare table to help organize the room!

Suzie Bulwan of Colorado would like to ask ladies who use oxygen how they fix their hair to keep it from getting tangled up in the cannula?

Constance Franklin of Mansfield, TX, has the most problems with shortness of breath in the mornings. After taking her nebulizer treatment, she pours herself a cup of coffee and adds two menthol cough drops to it. Constance reports they dissolve quickly to help clear the mucus in the back of her throat, clear her sinuses and help open up her breathing passages.

I was in the supermarket using my portable oxygen when I noticed a small boy looking up at me apprehensively. He glanced at me several times, trying not to stare. When I smiled, he came up and asked, "Are those boogers in your nose?" I suppressed a laugh and explained they were oxygen tubes that give me extra air to breathe. He sighed and with a shake of his head, said "Wow, I thought they were boogers!"

Terry Streller, Mariposa, CA

My daughter bought me a ticket on Southwest Airlines to visit my grandson. When I called to make oxygen arrangements, I was told it was impossible to take oxygen on the flight. I got out my most recent *Pulmonary Paper* and informed her that Southwest did accept portable oxygen concentrators. I spoke to a supervisor and in no time, all the arrangements were made! Thank you for keeping us informed!

Jane Knowlton, Boise, ID

Hey you gardeners with COPD, don't sit down! To dig and stay attached to your lifeline with ease, get four 50-foot tubing extensions and string each one out of the windows from all four sides of your house. Roll your concentrator to the window to attach the cords and garden away! Remember, when you dig in the dirt, you bury your troubles!

Martha Brookins, Ruldoso, NM

My portable oxygen unit was too heavy for me to carry. I bought a back pack with wheels and put my portable unit inside. Now I just pull it behind me. I can shop at the mall again!

Ione Kuzminski Waukesha, WI

I have bronchiectasis and a problem with raising secretions. My husband would clap on my chest four times a day but we both have arthritis. My doctor put me on 'The Vest'. It works great! You can get information about it on the Internet at www.thevest.com or by calling 1-800-426-4224. I have been using it for three years now. I can't say enough good things about this machine!

Alice Russo, Byron Center, MI

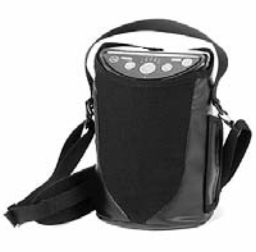
When I first started using oxygen therapy, I was depressed and would avoid being seen by people I knew out in public. Two years have passed and I now do not care who sees me. Oxygen therapy has been so beneficial! It allows me to function more independently without that horrible feeling of shortness of breath. I have been on two cruises and have been able to go camping in our trailer. I am truly blessed.

Maryann Tatro, Westfield, MA

Product Corner

New POC!

The portable oxygen concentrator (POC) selection will soon be increased to six. Invacare is introducing their XPO$_2$ Portable Concentrator that weighs only six pounds. The unit is currently awaiting FDA approval and will offer pulse-dose-only settings from 1 to 5. The XPO$_2$ measures ten inches high and has a 2.5-hour battery life at a setting of 2. You may attach an extra battery to the unit to double the usage time for a total weight of 7.5 pounds. We do not have many specifics at this time but the company literature tells us it is clinically robust! Visit www.invacare.com, search to Invacare Product Catalog - XPO2 Portable Concentrator.



New Cream Eases Dry Nose and Bleeding

RxStat pharmacists have developed a new cream to ease the dry nose and bleeding from using oxygen and CPAP nose pieces. The cream contains vasodilators to help reduce blood vessel size and bleeding.

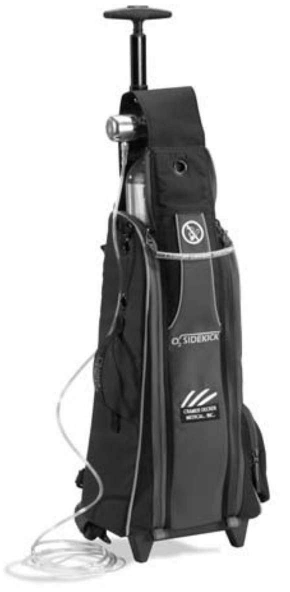
A 1-ounce tube of cannula cream is $8.99 (includes all s/h costs). Call 1-888-648-7250. Discount pricing is available when ordering in quantity.

Get a Discount on the O$_2$ Sidekick!

Cramer Decker Medical has designed a new, unique oxygen cylinder bag that begins as a roller bag but may convert to a backpack or to a shoulder bag. It can accommodate any size cylinder from an M2 to the large ME. You may read a full description of the five pound product at www.cramerdeckermedical.com/product.php?product_id=124. It is made from washable, heavy-duty denier and has many compartments with an easy-to-open zipper.

Scott Decker is offering *The Pulmonary Paper* members a 25 percent discount on the O$_2$ Sidekick ***until Christmas 2007,*** bringing the price down from $99.95 to $74.95. Now you know what to ask Santa for this year!

The company is located in California. To order, phone 1-877-222-0200 and be sure to let the representative know you are a member of *The Pulmonary Paper* to receive the discount.



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Respiratory News

London researchers have successfully implanted lung cells grown from embryonic stem cells into the lungs of mice. Stem cell therapy holds the hope of repairing diseased organs, such as the lung, with laboratory-grown tissue or cells. The British team had already cultivated lung cells and were testing to see if the cells were capable of embedding themselves into the lung. Not only was it successful, the specialized tissue was found nowhere else, but in the lung. Researchers know that human applications are far into the future as they need to determine the exact function and longevity of the grafted stem cells, as well as possible toxicity problems.

A study in the *American Journal of Respiratory and Critical Care Medicine* reports Canadian investigators found people with Chronic Obstructive Lung Disease on inhaled steroids were 70 percent more likely to be hospitalized with pneumonia and to have a more severe form of the disease. Today, about half of those with COPD are prescribed to take inhaled steroids. Further studies are being planned.

In the same journal is an article by researchers at Johns Hopkins University, who found symptoms of obstructive sleep apnea can be significantly reduced by using a nasal cannula to deliver warm, humidified air at a high flow rate.

Prolastin is a medication given to people with a genetic form of emphysema called Alpha One Antitrypsin Deficiency. It is now usually given intravenously weekly but Talecris Biotherapeutics, Inc. has demonstrated that using the new AKITA2® APIXNEB® system to inhale Prolastin results in very high levels of the drug being deposited in the lungs.

There has been a complete overhaul of COPD treatment guidelines by the Global Initiative for Chronic Obstructive Lung Disease (GOLD). The staging category has been eliminated and new recommendations for antibiotic use during exacerbations were made by health professionals from the National Heart Lung and Blood Institute and the World Health Organization. We will bring you more details in our next issue from the group who calls COPD “preventable and treatable.”