The Pulmonary Paper

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Dedicated to Respiratory Health Care

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Legislative Success!

Also inside:

Calling Dr. Bauer

Sharing the Health

Cycling with Oxygen

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On the cover: Jack Walden toasts to twenty years during a recent trip!

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What a difference twenty years makes! My children Ben, Adrienne and Julian in the fall of 1988 (top), ages 12, 6 and 2; and the bottom photo taken last month!

> **"Twenty years from now you will be more disappointed by the things that you didn't do than by the ones you did do." – Mark Twain**

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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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In September 1988, I had an idea to try and connect people who had respiratory problems but were afraid to leave their houses. The main idea I wanted to get across in our first issue (which took months to put together) was *You Are Not Alone!* We talked about pursed lip breathing, how smoking causes COPD and how you can call 1-800-222-LUNG to get answers to your questions. We learned it's good to eat six small meals instead of three larger ones and you should avoid gas-forming foods. We have seen many changes in the treatment of lung disease but there are some things that remain the same – *You Are Not Alone!*

Celeste

Significant Legal Decisions That Will Affect You!

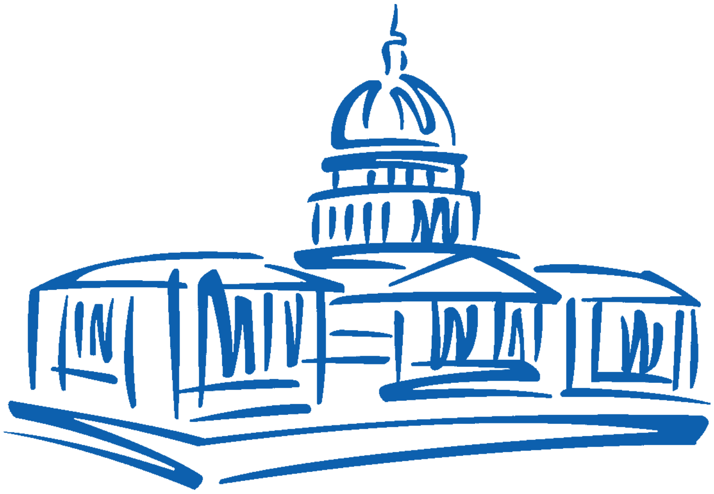
HR 6331 Legislation Passes!

Everyone who got involved by contacting their elected representatives can be proud of the passage of HR 6331 – Medicare Improvement for Patients and Providers Act of 2008.

President Bush, concerned how HR 6331 would be funded, vetoed the bill. Congress overrode the President's veto and the legislation became law this past July. There are three main components that will impact a person with chronic respiratory problems.

- **Pulmonary Rehabilitation Programs** – Medicare will now cover services provided by a Pulmonary Rehabilitation Program for people with COPD and other conditions. Until now, coverage was limited or non-existent, determined by individual states. By 2010, a new national benefit will be in place, eliminating inconsistent local coverages.
- **Oxygen Concentrator Ownership** – The Medicare requirement regarding transfer of ownership of an oxygen concentrator to the user after 36 months of continuous rental has been repealed. Home care companies will still have rental payments stopped after 36 months. If you were using a concentrator on January 1, 2006, payments will stop to your oxygen provider on January 1, 2009. We will know more how service will be affected once the final regulations are published.
- **Competitive Bidding Program** – HR 6331 delayed the durable medical equipment competitive bidding program for 18 months. If you recently switched oxygen providers because of competitive bidding, you now have the option of staying with your new company or returning to the one you were with before the switch.

Physician payments from Medicare were also scheduled for large cuts. Payments will now be kept at the current rate with a 1% increase in 2009.



We have received many phone calls from oxygen users around the country, all complaining Apria Healthcare, their home oxygen equipment provider, has taken away their liquid oxygen and replaced it with concentrators that refill portable tanks. An Arizona man, with the company for eight years, finds the tanks hard to maneuver, compared to his lightweight Helios. When he tried to get liquid oxygen from another local home care company, he was told, because he was with Apria for longer than three months, they could not service him.

We called and wrote Apria officials regarding their policy on liquid oxygen, but never received a response. (Apria Healthcare, a private company, has agreed to a buyout offer from The Blackstone Group. Shareholders will vote in September to approve making the company public.)

Let CMS Know How You Have Been Affected

NHOPA (National Home Oxygen Patients Association, www.homeoxygen.org), a patient-directed organization based near Washington, DC, is gathering information on how oxygen users have been affected by Medicare reimbursement changes. They will present the Centers for Medicare and Medicaid Services (CMS) the real life hardships people who use supplemental oxygen have to endure. Send specific information on problems receiving your oxygen equipment and supplies to:

NHOPA
8618 Westwood Center, Suite 210
Vienna, VA 22182-2222

Send the information via email at ExecOffice@homeoxygen.org or fax to 1-703-752-4360. Please include your name, a specific description of the nature of the difficulty, including the supplier, and written permission for NHOPA to share the information with the Centers for Medicare and Medicaid Services.

NHOPA would like to remind you, if a physician has ordered liquid oxygen, the company should supply it.

Need a 1 -line caption

I'd like to share some thoughts and observations about pulmonary medicine during the past twenty years. (But how can I be a senior staff member?)

One of the major changes in asthma and COPD management has been the explosion of new inhalers for disease symptom control. Combined bronchodilator/inhaled steroid preparations have revolutionized the control of chronic wheezing and cough. Standardized approaches towards treating COPD and asthma, with national and international approved guidelines, have resulted in more uniform and improved patient outcomes.

New diagnostic tests, including state-of-the-art CAT and MRI scanners, can now demonstrate exquisite detail of our lungs, frequently helping us to make diagnosis without invasive testing. Chest PET scans tell us whether small growths in the lung are likely to be malignant or not.

Many lung infections have become more difficult to treat, due to the development of antibiotic-resistant strains of bacteria, especially in treating forms of pneumonia and tuberculosis. Fortunately, we seem to be developing new antibiotics to measure up to the challenge.

A revolution in the field of biogenetics has promise to change the landscape of medicine. Although not yet realized, this technology should give us diagnostic tests for early cancer detection and drugs to treat cystic fibrosis and emphysema in the next twenty years.

Pulmonary fibrosis and pulmonary hypertension have proven to be very difficult to treat in the past. Research continues to tell us more and more about their cause.

One of the biggest challenges facing us is the cold hard realities of financing our medical care. Everything is more expensive: research expenses, hospital and drug costs, insurance and doctor fees, homecare and nursing home costs. I don't have answers here, but more careful and thoughtful use of the resources we currently have, need to be a large part of the picture.

Preventive care and educating our patients is the cornerstone of making us all a healthier. Congratulations to the *Pulmonary Paper* on your twentieth birthday and thank you, Celeste, for letting me be a member of the *Pulmonary Paper* family!

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

Rep. Brian Baird (D-WA) and Rep. Mike Castle (R-DE) have introduced the Pulmonary Fibrosis Research Enhancement Act – HR 6567. They each hold a personal interest as Rep. Castle lost his brother and sister and Rep. Baird's father passed away from the disease.

The Coalition for Pulmonary Fibrosis (CPF) now needs your help. This bill would increase federal research funding for idiopathic pulmonary fibrosis (IPF) and create a national patient registry which will greatly aid research into the disease. Very little is known about it and there is no known cause or FDA-approved treatment. This bill would bring much needed help to the more than 128,000 people affected each year.

When passed, the PF Research Enhancement Act would also mandate the creation of a National PF Action Plan, which would focus on strategies to improve public awareness of PF and accelerate patient and medical education strategies. It would establish a National PF Advisory Board, which would make recommendations to the NIH and CDC concerning the structure and management of a PF patient registry. Establishing a National Summit on PF would foster collaboration between Federal Agencies, researchers, patients and advocates to identify new approaches to research and treat PF.

Visit the new, redesigned CPF website at www.coalitionforpf.org and click on 'advocacy' to get involved. One easy click will send a letter to your representatives in Washington! Use the CPF's new online advocacy program to contact everyone you know. Ask all of your friends to please take action – every contact moves us closer to success. You may call the CPF at 1-888-222-8541 for more information.

For those interested in current PF clinical research studies, visit www.coalitionforpf.org/research.

Novartis recently initiated enrollment of a Phase II clinical trial investigating QAX576 as a potential treatment for IPF. The purpose of this study is to investigate how QAX576 affects levels of interleukin-13 in patients with IPF. The study seeks to enroll up to 50 patients. You may contact Novartis at 1-862-778-8300 for more information.

InterMune, Inc.'s development of Pirfenidone for the treatment of IPF has received "Fast Track" designation from the FDA, meaning it is intended to treat a serious or life threatening condition.The company hopes to have the Phase 3 Results of their CAPACITY program in January of 2009.

On the horizon is Dr. James Crapo's research into a new drug that mimics superoxide dismutase, an important antioxidant defense in nearly all cells. It is a treatment he hopes will be a viable option for PF in the future. Dr. Crapo's brother is Senator Mike Crapo, who has led several initiatives in the U.S. Congress to raise awareness and funding for lung disease.

Ask Mark …

Mark Mangus, RRT
EFFORTS Board

Alan from EFFORTS asks Mark, "What is the difference between the medications, Perforomist and Brovana?"

Mark replies, "There is a distinct and consequential difference between Perforomist (Formoterol Fumarate) and Brovana (Aformoterol Tartrate). They are the same in that they are both long-acting, beta-agonist bronchodilators. They are also the same in that they are solutions for nebulization. But Aformoterol has an "isomer" removed, making it stronger in action and longer lasting. It is like comparing Albuterol and Levalbuterol (Xopenex), the inactive, or counteractive component of the drug has been removed. It is known that the single-isomer versions of these drugs tend to cause few to no side effects, like pounding heart, shakiness, gastric irritation and the rare increase in heart rate."

Melva writes, "I've lost about 30% of my body weight in the last year and am trying to gain at least 15 lbs. I'm eating three or four small meals a day and taking Ensure, I could sure use other suggestions!"

Mark says, "People with emphysema have shown a 25% increase in energy expenditure. Eating three to four meals a day is good – if the total calorie count is sufficient. Ensure is a good supplement, you can add a tablespoon of canola oil to it and increase the calorie total by 125 calories without changing anything more than the texture. It is likely that if you aren't averaging an intake of more than 3,000 calories in a 24-hour period, then you are falling short of your needs to gain body mass. Adding peanut butter, avocados, fat-filled gravies and cheese sauces are good ways to significantly increase the total calories of many dishes. Fats yield nine calories per gram compared to four calories for protein and carbohydrates. The fat is good for you and provides more calories. If you don't find cow's milk to your liking as much as soy milk, you can always add vegetable oil to the soy milk and get the additional fat calories without fear of altering the taste appreciably."

Nan from California wonders, "I saw my pulmonologist and asked why I needed to be on continuous flow. He said it is better for those who are mouth and shallow breathers. Does this make sense?"

Mark explains, "Even those who breathe through their mouths can get plenty of oxygen as long as they are not blocking off their nose. The old myth about "shallow breathers" has never been borne out by any studies that I have seen.

You will get more oxygen with a pulse-dose setting than from continuous flow. When the oxygen is delivered in a bolus or "puff" during the first one-third of inhalation, it will get deeper and spread farther throughout the lungs than the same amount given in continuous flow and breathed in over the entire inhalation. That's because the gas taken in during the last third of each inhalation never has a chance to reach deep enough into the lungs to exchange gas with the blood. It stays in the bronchial tubes which don't have gas-exchanging units within them. Conserving devices make your oxygen supply last longer because they cut out the wasted oxygen that is delivered when you're not breathing in.

When you are breathing faster, you will always lose with continuous flow as compared to pulsed conservers and demand flow. The conservers will continue to deliver the same sized pulse while you breathe faster (until you reach the maximum rate capacity of the device, usually between 25 and 40 breaths, depending upon the brand and model). With continuous flow all you do is take a steady flow and chop it up into smaller pieces, of which only two-thirds can get to where it needs to, in order to exchange with the blood. By default, the conservers will always give you more oxygen than can continuous flow!"

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.

Actor Bernie Mac Succombs to Pneumonia

We were saddened to hear the news that actor Bernie Mac passed away from pneumonia. The actor had been diagnosed with sarcoidosis for more than 20 years. Medical experts suspect this may have played a role in his death. Bernie Mac was 50 years old.

The National Heart Lung and Blood Institute describes sarcoidosis as a process where inflammation produces tiny lumps of cells in various organs. The lumps are called granulomas because they look like grains of sugar or sand. They can be seen only with a microscope.

The tiny granulomas can grow and clump together. If they form in an organ, they can affect how the organ works, which causes symptoms.

Sarcoidosis can occur in almost any part of your body, although it usually starts in the lungs or lymph nodes of the chest and almost always occurs in more than one organ at a time. In the active phase, the granulomas form and grow. Shortness of breath and chest pain can develop, scar tissue forms and fibrosis results. In the nonactive phase, the inflammation goes down, and the granulomas stay the same size or shrink. The scars may remain and cause symptoms.

The course of the disease varies greatly. In many people, sarcoidosis is mild. Symptoms may go away within a few years. In others, the inflammation remains but doesn't get worse. In still others, the disease slowly gets worse over the years and causes permanent organ damage. Although treatment can help, sarcoidosis may leave scar tissue in the lungs, skin, eyes, or other organs.

There is no known way to prevent or cure sarcoidosis. Black women and people of Scandinavian descent have the highest rates of occurrence. It is rarely fatal and tends to appear between the ages of 20 and 40. Corticosteroid medications are considered the first line of treatment for sarcoidosis that requires treatment. Drugs as cortisone and prednisone will decrease inflammation and prevent organ damage. Imunosuppresants as methotrexate and the antimalarial drug Plaquenil® have found to be helpful. CellCept® and Imuran® are usually treatments for people who have received organ transplants but may be used to treat sarcoidosis. Cytoxan®, a cancer treatment, may be tried in serious cases.

Remicade® given by infusion and Humira® or Enbrel® given by injection have also been used. Under investigation now is Thalomid for skin problems, Trental for leg pain and antibiotic tetracyclines for infections in sarcoidosis.

Identified in the late 1860s, sarcoidosis was once thought to be an uncommon condition. It's now known to affect tens of thousands of people throughout the United States. Because many people who have sarcoidosis have no symptoms, it's hard to know how many people have the condition.

Sharing the Health

Dr. Ron Karpick

Dr. Ron Karpick is a Virginia specialist in Pulmonary Disease, Internal Medicine and Geriatric Medicine who has also been involved with EFFORTS. He recently read an article investigating deaths from fire, caused by people on supplemental oxygen therapy, who were smoking. Dr. Ron thought this subject deserved some attention. He says, “Fortunately the event is not common, but it is not rare either.”

The report in the weekly report from the Centers for Disease Control looked at the death statistics from four states over a seven year period. It showed thirty-four oxygen users were smoking at the time a fire began. Three were household members of smokers and one was a non-smoker on long-term oxygen who was unintentionally ignited by a smoker living in the household. The bedroom was the most common site of the start of the fires and the majority of fires occurred between midnight and 8 am.

Dr. Ron believes what is important about this article is that “individuals who continue to smoke should not do so while breathing supplemental oxygen. I do not believe there are any studies that show that there is any benefit given to persistent smokers on long-term oxygen. Smoking produces carbon monoxide in the blood stream which would negate the benefit of oxygen therapy on the heart, blood vessels and brain.

Oxygen will not explode, but it enhances burning. Oxygen makes flammable materials burn faster and hotter. Homes should have smoke alarms and fire extinguishers, so that if a fire does start, the alarm would sound, the fire department would be called, and the people would be evacuated. If the fire was small, it could possibly be extinguished by someone in the household. Better still, a sprinkler system could start automatically, while the occupants were being evacuated. Every home should have an evacuation plan.

Oxygen is a valuable medicine, it is not to be abused. Its abuse can have serious consequences for the user and for our loved ones.”

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.

Unbelievably, a 90-year-old Michigan woman was critically burned when smoking while on oxygen, even though she was hospitalized for a similar incident the previous May!

From our premier issue, we would like to present “Constructive Attitudes and Behaviors for Rehabilitation” that we think you still be inspired by after twenty years.

- *Always get dressed first thing in the morning. Staying in bedclothes promotes illness rather than wellness.*
- *Visit 3 to 5 people outside your home during the week.*
- *Do not talk about your disease, other than a brief polite response to persons who inquire about your health.*
- *Occasionally, exercise to the point of discomfort, then, by voluntary effort, mind over matter, relax, do pursed lip breathing and breathe easy. You are in control of your symptoms. Shortness of breath is unpleasant but not harmful.*
- *If you begin to feel depressed, don’t just sit there until you lose the ability to act. Do something!*
- *Do not let others do things for you which you could do for yourself, even if discomfort results.*
- *Persuade your spouse or significant other, to spend one day a week away from you.*
- *Make a list of short-term goals, such as walking a certain length or going out, and then reward yourself for good behavior.*

Throughout the years, our readers have enjoyed *Sharing the Health*. Some of our favorite tips:

Soap chips or shavings, placed underneath your bed sheets, or bar soap rubbed on your calves before sleep, prevent leg cramps. No one can offer an explanation why, but so many of you have said it works!

In the shower, use a bath seat and a hand sprayer. If you use oxygen, drape your tubing over the shower rod. When you get out, put on a terry cloth robe instead of drying off with towels. Have another chair or stool *to use with a low mirror to shave or put makeup on. Shorter hairstyles that are easy to care for may be helpful.*

Do not wear clothes that are tight, they may restrict your breathing. People with emphysema often have an increased chest diameter. Ladies find camisoles easier to wear than bras. There is no rule that you have to wear girdles or pantyhose. Men find suspenders easier than belts. Using a long shoehorn for slip-on and velcro shoes beats trying to bend over and tie shoelaces.

Carry a small basket with medications and other items you need frequently throughout the day. It will save steps. Use a long-handled gripper to avoid bending for things in high or low places. Prepare and pace yourself for activities.

Tai Chi is a favorite exercise for people with lung problems and it has recently been found to help older people sleep better.

And the tips just keep on coming!

I put my "E" oxygen cylinder (that I have named Ezmeralda) in her cart with a fifty-foot hose and away we go to our community pool. Ezmeralda lies quietly near the edge of the pool and allows me to do laps. It is easy to do exercises in the water. If there are not too many people, I can swim laps across. Everyone is very kind and tends to keep out of the way of the hose.

Nancy Miller, Gulfport, FL

I am sending a very big thank you for sharing helpful hints. I read about a lady that blew bubbles to help her breathing. I thought it would be fun but did not realize how much it would help me! I went to my doctor after blowing bubbles for a month. Amazingly, he told me my lung capacity increased 5% from my last test.

I am 88 years old and still drive my own car.

Evelyn Edleman, Camanche, IA

It is really nice to know that I am not alone with my emphysema. I have a tip to help the air circulate around your concentrator. I purchased "bed risers" which come in a box of four. I put one under each wheel of the concentrator. It seems to distribute the air so it doesn't overheat at the bottom. It keeps the area a little cooler too. I found the bed risers at Bed, Bath and Beyond, they are reasonably priced and really work!

Jacquie Tompkins, Glendale, AZ

Plan Ahead and Get Your Flu Vaccination!

Be sure to make plans to get your annual flu vaccination. The FDA has updated the vaccine with three new strains, rather than the usual one or two. There should be no danger of a shortage of serum this year, as there are six versions of flu vaccine being distributed. FluMist, a live vaccine given nasally, is recommended for those ages 2 through 49. People with COPD should avoid FluMist. Plan to be protected by Election Day!

You might want to check with your physician when the last time you received a pneumonia vaccination was. The doctor may want you to receive an additional dose if it has been five years or longer.

Traveling Tales

San Francisco to Tijuana on Two-Wheels

There have been many articles written about hitting the road. This one holds a lot of meaning for one person with respiratory problems. Four years ago, oxygen user Mark Junge, completed a 3,400-mile bicycle journey from San Francisco to New York City. Mr. Junge is a retired historian and photographer from Cheyenne, Wyoming. In 2006, Mark rode from New York to Cape Spear, Newfoundland; the next year, he bicycled from San Francisco to Vancouver, Canada. Now 64 years old, Mark is at it again, completing another trip by bike from San Francisco to Tijuana, Mexico. Using a Sequal Eclipse portable oxygen concentrator (POC), Mark hopes to show everyone that being on oxygen doesn't make you home-bound!

For those who purchased an original Eclipse POC, call the company that you bought it from for instructions on how to upgrade to the new AutoSat Technology. This gives you consistent oxygen delivery at higher breath rates.

Travel for those needing respiratory equipment has definitely gotten easier over the past twenty years. When we started to write this newsletter, we reported on how people would have their vans refitted to get the electrical systems ready to accommodate the power needs of an oxygen concentrator – which weighed at least 50 pounds. Today, you can slide your POC off your shoulder and plug it directly into the power outlet.

Favorite Travel Tips

- You can never start too early to plan your arrangements. Plan to double and triple check them before you leave home.
- Buy travel insurance, just in case.
- If not already physically active, consider joining a pulmonary rehab group to be in the best possible condition to travel.
- Bring an extension strip or plug to share electricity with computer users in airports.
- Have your oxygen prescription updated at least once a year and have it laminated so you may carry it with you. Make sure it states that you use a nasal cannula if using airline oxygen or you may end up with a mask!
- Bring a filled prescription of antibiotics with you. If your physician permits, one for prednisone too.
- Ask for wheelchair assistance – this is no time to be proud! It not only saves your breath for fun things to do but gets you to the front of the line!
- If going overseas, don't plug your nebulizer into the hotel outlet – it will blow up!
- Watch your salt and dietary intake while on vacation – retaining fluid is not fun.
- Always bring extra everything, even though you and your traveling companion look like pack mules!
- If you ask a friend or relative to travel with you, tell them honestly that you may have limitations and may need their help. We have seen many friendships end when one person did not live up to the other's expectations on the trip.

SeaPuffers Continue to See the World!

Pam from SeaPuffers has arranged a week-long Western Caribbean cruise that leaves from Galveston, TX, on February 8, 2009. There is also a ten day trip through the Panama Canal leaving on February 17, 2009 from Fort Lauderdale, FL. Call Pam at 1-877-473-2726!

Product Corner

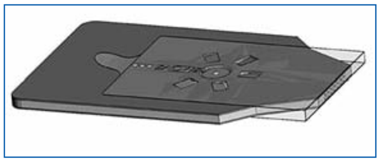
The Oxy-Sure *Buddy*™ is a device to stabilize your nasal cannula during sleep and activity. Roberta McGlothen, founder of Oxy-Sure Company LLC, says the patented *Buddy* is made of light weight, breathable material. Designed for her Mom, Roberta says not only do oxygen users benefit, but their caregivers are secure knowing they do not have to worry during the night. The *Buddy* also relieves tubing pressure on the ears.

For a sample of the Oxy-Sure *Buddy*, send $2 with your name and address to: Oxy-Sure Company, LLC, 13930 2nd Avenue West, Orofino, ID 83544.

The *Buddy* usually retails for $3.89. You may also call for further information at 1-866-476-3800 or visit www.oxy-sure.com.

Dr. Hana from BeWell Health wanted to share information regarding a nose wash system first designed for children but easy for adults to appreciate. Dr. Hana believes daily washing will reduce allergies, cough and post-nasal drip.

For further information and to order the $20 starter kit, you may call 1-877-853-7873 or visit www.nasopure.com.



Aespironics, a company from Israel has developed a credit card-sized inhaler designed to deliver medications directly to the lungs. The technology included in the company's dry powder inhaler, which made its debut in June, also reduces the cost of the device. It is not currently available in the United States.

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Dedicated to Respiratory Health Care

Respiratory News

Haemair Ltd., a company based in the United Kingdom, is developing a device that may act as an artificial lung and be an alternative to people awaiting a lung transplant. The Haemair Device directly removes carbon dioxide and adds oxygen to blood bypassing the lungs. It is devised to keep up when someone who is wearing the device has an increased respiratory rate.

You may learn more at the company website, www.haemair.com.

Drug-resistant tuberculosis is a diagnosis that has frustrated many health professionals. *The New England Journal of Medicine* reports an individualized outpatient therapy program can stop the disease from progressing.

Drug treatment and additional services, including surgery, adverse-event management, and nutritional and psychological support, were given to 810 patients with unsuccessfully treated tuberculosis. Clinicians developed regimens that included five or more drugs to which the infecting strains were likely to respond. The lead author would like the world to know that "drug resistant TB is not a death sentence and effective treatment does not require hospitalization or indefinite confinement of patients."

Normally, everyone loses some lung function as they age. Your Forced Expiratory Volume in one second (FEV_1) is measured when you take a deep breath and exhale it as quickly as you can. When people smoke or they have COPD, this measurement declines more quickly.

For the first time, we have medication that can slow the progression of COPD. People who took Advair (a combination of fluticasone proprionate, a corticosteroid and salmeterol, a bronchodilator) reduced their loss of FEV_1 by 16 ml/year. Dr. Bart Celli reports these results in the *American Journal of Respiratory and Critical Care Medicine*. Researchers looked at over 6,000 patients' data. Using Flovent and Serevent, the same drugs that make up Advair, had similar benefits.