



The Pulmonary Paper

Dedicated To Respiratory Health Care

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Canadian Drugs

The House recently passed a \$91 billion fiscal year 2008 Agriculture appropriations bill (HR 3161) with a provision that effectively would allow U.S. residents to purchase lower-cost prescription drugs from Canada and other nations. Under the provision, the FDA could not use federal funds to enforce a ban on prescription drug reimportation.

Critics of the provision raised concerns about the safety of getting prescription drugs this way. A policy statement issued by the Bush administration “strongly opposes” the provision, but did not include an explicit veto threat.

Source: *emaxhealth.com*

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A Call to Action

The National Home Oxygen Patient Association (NHOPA) urgently needs our help!

The House of Representatives has taken action that seriously threatens the availability of portable oxygen equipment. It also mandates that oxygen users accept ownership of their devices after 18 months of continuous use, not the 36 months mandated by Congress two years ago. If enacted, these changes will take effect January 1, 2008.

NHOPA believes that if this legislation becomes law, suppliers will likely stop providing lightweight oxygen systems as the payment by Medicare will not cover their costs. The NHOPA Board strongly believes that all portable systems, including portable oxygen concentrators, transfill systems, liquid systems and lightweight portable systems all should be kept at the 36 month payment threshold. They also believe that transfer of ownership from the oxygen supplier to the Medicare beneficiary is unacceptable. Such a transfer of ownership places patients at risk for maintaining medical devices and puts an impossible burden on manufacturers to keep track of devices in the event of recall, replacement, required maintenance, etc.

Write to your two Senators immediately, and urge everyone

you know who is also using supplementary oxygen to do so. E-mail is preferred, and fax is also acceptable. Phone calls to Senate offices are also encouraged. If you have access to the internet, go to www.senate.gov and click on “Senators” to find your senators. This will provide a list of all 100 senators with phone numbers and links to the Senators’ websites. Those websites provide fax, phone and e-mail information. If you don’t have internet access, you may call the Senate switchboard at 202-224-3121 and ask to be connected to your Senator’s office.

Identify yourself by name and age and that you use oxygen. Tell them the House of Representatives has approved legislation that is intended to reduce payment for stationary equipment, but it would make access to some portable oxygen systems nearly impossible. The House has also taken action to expedite ownership transfer of oxygen systems to patients after 18 months of continuous use. We believe that responsibility for these FDA approved devices should lie with the supplier, not with the patient. You want to make sure that any action taken by the Senate related to Medicare guarantees that all portable systems continue to be paid for 36 months and that ownership transfer is repealed.

Thank you for your help!

Feelings

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

- Feeling OK
- Feeling Worse
- Feeling Afraid
- Feeling Sorry
- Feeling Sad
- Feeling Mad
- Feeling Useless
- Feeling Ashamed
- Feeling Love of Family
- Feeling the Caring of Friends
- Feeling Glad for each Day
- Feeling Happy to be able to continue the Journey



PV, Athens NY

I'd like to tape the nose and mouth of Republican Bill Thomas of California and see if he would consider oxygen a luxury.



TS, Mariposa, CA

My 63 year old mother has COPD and I am her caregiver. She has 30% of her lung capacity left. I hate to see such a young person struggle so much to do daily activities. The anxiety

goes onto the whole family.

JT, Florida



Why do I/Me/Someone get depressed and stop being active like going to rehab, exercise, traveling and attendance at social functions?

IO, Sherwood, OR

After raising five children and two grandchildren – gardening and working full time – how do I adjust to using oxygen and still not be able to do what I did?

LE, San Diego, CA

Can you tell me how we can send a spaceship to the moon and not make a lightweight oxygen tank that can be refilled on a home concentrator system? Right now I need to go to a chiropractor every three weeks because of carrying a small metal tank.



SD, Garrison, ND

You want to know why I hate COPD? I feel like the morning after when I have not been anywhere the night before! I am on my 6th year with COPD. I had a bout with breast cancer and 21 years after that had colon cancer. My knees are bad and I really need surgery but they will not do them due to my lungs and the fact that I am now 86. But I want to keep on living, I still have things I can do. With the help of walkers and stores with electric carts, I thank God for each and every day. I will take it as it is.

EE, Camanche, IA

Editorial

Now is the time for all good people with lung disease to come to the aid of their peers. Call, email or visit your elected officials and tell them you need their concern on the issues of oxygen reimbursement and pulmonary rehabilitation!

Since my children are now grown and out of the house, we are now raising my parents who have moved in with us! Look how Matt and Mary have grown!



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Editor: Celeste Belyea RN, RRT, AE-C
Ass Editor Dominic Coppolo RRT, AE-C
Medical Director: Dr. Michael Bauer

Calling Dr. Bauer ...

Dear Dr. Bauer:

How does you feel about sleep aids for those of us with emphysema? There seems to be several schools of thought about this. G.J., Florence, AZ

Dear G.J.,

All of us have some problems getting a good night sleep every now and then. Patients with lung disease often have poor sleep quality on a more chronic basis. There are many reasons for this. Emphysema patients have problems with airflow obstruction resulting in cough, wheezing and shortness of breath. If these occur on a regular basis, you can easily imagine why sleep can be poor. Make sure you use your bronchodilator inhalers before bedtime to promote a restful sleep. Some of the longer twelve hour acting inhalers can be especially beneficial.

Adults tend to breathe slowly and with more shallow breaths while sleeping. This results in reduced oxygen levels. For those

with emphysema, low oxygen levels during sleep can either keep you up or prevent your body from reaching the deep restorative stages of sleep. Night time oxygen testing while sleeping with a pulse oximeter is a safe and easy test that is being used more often to see if this is a problem.

Let your doctor know if you are a loud snorer, especially if you seem too tired during the day. A sleep study to rule out sleep apnea may be needed. When sleep apnea is treated, improved sleep efficiency and more restful sleep should follow.

Many over the counter sleep aids are available in the local pharmacy. In general, most are safe, but all should be used with some caution, and not every night in those with lung disease. Pills that cause too much sedation can stress already low oxygen levels and do more harm than good. This is especially true for the stronger prescription sedatives.



Have a question for Dr Bauer?
You may write to him at
The Pulmonary Paper
PO Box 877
Ormond Beach, FL 32175
or by email at Belyea@aol.com

Good sleep hygiene entails getting into a restful routine before bedtime. For some it's a warm glass of milk, or reading a book or watching TV. Pleasant dreams to all!



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Rescue Me

When disaster strikes, do you have an emergency plan how to get oxygen and other needed medical equipment?



Doris Tarter of Minden, NV would like to hear from others who have been in situations of hurricanes, fires or floods and were forced to leave their home and the source of their supplies.

Many head to emergency shelters, hospitals or fire stations, who may have oxygen for you to use.

A Florida Area Agency on Aging recommends you register with your County Emergency Management Agency and your local Electric company so they are aware of your special needs. If you receive warning that you may have to leave your home, you should make a checklist now of things that should be done that may include to get prescriptions filled; get cash and have your

keys, eyeglasses, dentures, hearing aids with extra batteries, prosthetic devices, canes, etc. Make arrangements for pets. Buy extra batteries for portable radio and flashlight. Turn off all utilities at the main power switch. Bring outdoor possessions in or tie down securely. Move valuables to the safest location in the home away from windows and possible rising water. Have someone help cover windows and doors if possible.

Have a notebook or binder prepared that contains important information you will need quickly as your social security and insurance cards; medical history and medication list; copy of your will and advance medical directive; bank account and credit card numbers and contact information of family members. You may want to bring valuable papers and photographs in a plastic zipper bag.

When you evacuate you will need to take provisions with you to make your temporary stay

more comfortable as personal hygiene items such as soap, deodorant, shampoo, toothbrush, toothpaste, washcloths, towels, etc; special dietary foods, if needed; books, magazines, cards; change of clothing and collapsible lawn chair, blanket or sleeping bag.

Cyl-Fill

Cyl-Fill is a new home oxygen option available from Responsive Respiratory.



There are now units on the market that allow you to fill portable oxygen tanks from a concentrator. This system fills the tanks directly from a large oxygen cylinder. A supply cylinder would contain enough volume to fill 17 smaller M6 portable cylinders. It takes approximately 15 minutes to fill a portable tank.

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Peak Flow Meters and CO2

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.



Mark Mangus, RRT
EFFORTS Board

Jack from EFFORTS recently asked Mark about peak flow meters and how accurate they are.



A peak flow meter measures your highest expiratory flow rate when you forcefully exhale in a "huff or fast blast." Accuracy of peak flow is strictly dependent upon patient

effort and performance. People with COPD have low flow rates which do not significantly change across a wide spectrum of conditions. If your peak flow reading is less than 200 liters per minute, a peak flow meter is not recommended. Those with asthma have great changes in peak flow rates. When used daily, a drop in peak flow readings, alerts the user to an impending asthma attack so they may take action quickly.

There is absolutely no evidence that the same holds true for a COPD exacerbation. Asthma is of an acute nature and COPD is not. The swelling in the airways of those with asthma occurs hours before the onset of an attack. That inflammation is what invokes significant changes in peak flow long before the full blown attack occurs. Changes in the airways of those with COPD do not occur as immediately or as severely as they do with asthma. Peak flow is always low and changes a relatively small amount from steady state to full blown exacerbation. You should be very careful when using peak flow as part of your COPD management regimen. The more severe your COPD, the less weight you should place on it.

Alan B was wondering if he could train himself to deep breathe in order to increase oxygen levels and clear carbon dioxide (CO₂) from his lungs.

The reason we breathe in and out is solely to eliminate CO₂. Your breathing efforts should not be aimed at thoughts of oxygenation as much as at CO₂ reduction. Oxygenation is a passive function of breathing and will take care of itself as long as you breathe effectively to reduce CO₂. While it is always good to stop and take a few deep breaths, cleansing breaths as they might be referred to in yoga and relaxation techniques, that is something you can do only periodically and for a relatively short duration. If you think you can reduce CO₂ retention or somehow train yourself to do other than the natural method of smaller volumes during quiet breathing, I have seen no evidence that such a thing can be done.

You can lower your CO₂ by taking deliberate deep breaths while resting over a period of time. It will lower the CO₂ only during the time you are being deliberate about your breathing. You will revert back to your smaller volume breathing pattern as soon as you stop thinking about it. That is the nature of the beast. Also, when you sleep, you cannot be deliberate about your breathing pattern.



The kidneys compensate for the change in CO₂ by retaining bicarbonate to 'buffer' the system and maintain a normal pH. These are metabolic changes over which you have no deliberate control. When pH is normal, a must for physiologic stability, it does not matter how diseased and dysfunctional the lungs may be. CO₂ is not a concern to the body, overall. The reason folks become CO₂ retainers is because the kidneys have done their job to maintain a normal pH and let CO₂ do what it will. I've said it before and I'll continue to say it: "People obsess over CO₂ - over which they have no control, in deference to the consequential parameter; the pH!"

Fibrosis File



Along with COPD, mortality rates from pulmonary fibrosis have increased significantly, especially in women, and are predicted to continue to rise, according to researchers from the University of Colorado who said, "Results suggest that PF should no longer be considered a rarity. These findings indicate an important and growing problem and provide an argument for more resources focused on research and therapy for this disease."

Officials are listening. Following the death of his colleague, Congressman Charlie Norwood of Georgia, from idiopathic pulmonary fibrosis (IPF), Congressman Brian Baird has joined Congressman Nathan Deal in introducing H.Con.Res.182 into Congress. The proposed legislation, in part, seeks to recognize "the need to pursue

research into the causes, a treatment, and an eventual cure for idiopathic pulmonary fibrosis." It also pledges to support the goals and ideals of National IPF Awareness Week, September 22-29, 2007. According to Baird, whose father died as a result of pulmonary fibrosis, the disease is often overlooked. He hopes the passage of this resolution will lead to the aggressive pursuit of research opportunities into the causes of the disease, a treatment, and eventual cure.

Mark Shreve, CEO of the Coalition for Pulmonary Fibrosis (www.coalitionforpf.org), says the legislation represents an important step for the IPF cause for several reasons:

- It advocates for patients who suffer from IPF. In the past five years, IPF prevalence and incidence has increased 156 percent; yet there remains no FDA approved treatment to combat this deadly disease, and research funding remains unacceptably low.

- It creates the foundation on which all future legislation involving IPF may be based.
- It defines the challenges facing the IPF community in the Congressional Record.
- It becomes a permanent vehicle for educating Members of Congress.
- It will lead to greater public awareness of IPF.
- It will initiate a dialog in Congress to increase attention and funding given to the deadly disease that kills 40,000 Americans each year, as many as claimed by breast cancer.

In other news, Neopharm, Inc. has entered into an exclusive patent license agreement with the National Institutes of Health for the development of nebulized Cintredekin Besudotox for the treatment of IPF and asthma. Pre-clinical studies appear to be promising, including preliminary evidence of the reversal of the disease and its scarring in the animal models of IPF.

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Travel Tips

Holly Marocchi RRT has logged thousands of miles escorting respiratory people on cruises and trips. She has compiled this list of travel tips to help your vacations be a little more stress free.

Just in case, bring a filled prescription of antibiotics and/or prednisone in case you begin to feel any unwanted symptoms. It will save time and money.

Even though you are away from home, you can always call your own physician to get their advice.

Bring a first aid kit with help for problems that may often affect you - as antacids for an upset stomach or bandaids for skin tears. Oxygen supplies are very hard to find in a foreign country. If you have allergies, bring your rescue medications. Many caregivers call themselves a "pack mule!"

Have your medication list, brief medical history, including blood type and allergy information, stored with your passport.

Carry Purell or disinfectant cloths with you.



Jack Walden plays a Viking to the delight of his wife, Joan

Traveling Tales

It is the season of the POCs - Portable Oxygen Concentrators. The airlines continue to support the use of AirSep's Lifestyle and Freestyle, Inogen One, Sequal's Eclipse and Respironics' Evergo POCs.

United Airlines remain the main domestic airline who will not allow POC use onboard. We spoke to a representative who told us the same thing they have for the past three years, "We are waiting approval."

Bob Kern of Warrenton, VA wrote to say he had no trouble with airport security when flying to Moscow and Tel Aviv with a POC. Thirty Sea Puffers traveled across the pond to London and boarded a cruise ship that took them to exciting cities in Scandinavia. Tour buses met us as we docked for our own personalized tours of Coophegan, Helsinki, Stockholm, Oslo, Tallim and St Petersburg. We got to stand in front of a Leonardo daVinci painting and in the dining room of Peter the Great. We took our shoes off to stand in the Baltic Sea and stood in the rooms where the Nobel Prizes are awarded. There was something different about this trip - nearly everyone was using a POC. Beep, Beep .. whose alarming? Someone's battery is running low, can I borrow one of yours?



SeaPuffers pose in front of the Summer Palace of Peter the Great

There was also time to share tips. We heard if you are having problems with Sequal batteries running out of life quickly, run the battery all the way down before charging back up again. Jack Walden was given a mask instead of a cannula when he boarded the plane. He had them cut the mask and attached a spare cannula he had brought along. Marshall Lacooff suggested having your doctor specifically request a nasal cannula in the oxygen prescription. Ed Reardon had just had his home painted and recommended using Sherwin Williams "green" line of odorless paint.

Come to Las Vegas September 30 through October 4! Pam has arranged a non smoking suite-hotel. There will be a dinner cruise on Lake Mead and a tour of the Grand Canyon. Speakers scheduled include Mark Mangus and John Goodman speaking on TransTracheal Oxygen. Call Pam at 1-877-473-2726 to sign up for sightseeing and the support of old and new friends!

Sharing the Health

Judith Dankel of Reno, NV, writes that her post pulmonary rehab group brings encouragement, exchange of new information, laughter and exercise. They are called the Pursed Lip Pals. Once a month they have a pot luck dinner!



Many people have written to inquire if there is a rehabilitation program or support group in their specific area. EFFORTS at www.emphysema.net,

maintains a current listing for those with COPD at <http://emphysema.net/bindex.html> You may also call your local American Lung Association or area hospitals for information. The Pulmonary Hypertension Association has a listing at http://www.phassociation.org/Support_Groups or you may phone 1-800-748-7274. The Coalition for Pulmonary Fibrosis information may be found at <http://coalitionforpf.org/Patients/support/default.asp> or phone 1-888-8541.

Marie Hansen of Fresh Meadows, NY carries *Wet Ones* or small packets of hand sanitizer as part of her Safety First plan. She also washes her hands thoroughly after touching commonly used surfaces for the best protection.



Marilyn Foster of Escondido, CA, has a simple tip to make lives for ladies a little easier. Try to buy tops that use front buttons. They are easier to get on and off!

I'd like to share this tip about moisture in the tubing connected to your oxygen concentrator. All you have to do to get rid of it, is to connect it to your nebulizer and blow it out!

*Ruby Pavy
Lakeview, OH*

So many of us have had the experience of the trailing cannula that has the potential to pick up a lot of germs. I use a Hefty Zipper bag for protecting it, which is very useful for when I am out and about and for storage.



A product called RespiClean is now available. Developed by a physician who was diagnosed with sleep apnea, it has been formulated to deodorize and clean nebulizers, concentrators and CPAP masks. It is a great improvement in cleaning equipment. The solution is also available in a small sized spray that is a very easy and inexpensive way to clean the end of a cannula. I have mine in my purse at all times. You can order these products at 1-512-864-3137 or on the web at www.patientsleepsupplies.com

I am really pleased with them and think you would be too.

*Mary Ann Barbour
Georgetown, TX*

About a year ago, I was diagnosed with NSIP - Non-specific interstitial pneumonitis. I have been plagued with mucous plugs in my lungs. My doctors had me on nebulizers with acetylcystine and albuterol, which worked, but irritated my throat. I went to a Homeopath who pounded on my chest to help move the plugs. Then one day in the hot tub of



our health club, I thought of using the jet streams to pound my chest all around, front and back, while deep breathing, holding and fully exhaling the steam. It works! Now I go 2-3 times per week and leave with clearer lungs and no side effects. Try it, you'll like it!

*Michael Tully
Garrison, NY*

I just celebrated my 80th birthday and cope by doing Yoga, riding a stationery bike and using a treadmill, almost every day. I keep on keeping on.

*Pauline Hessel
Luxemburg, WI*

And More Sharing the Health

It has been over a year since I was diagnosed with COPD. I always wonder how I ended up with it as I never smoked. I did do a lot of cooking in seminars and large communities for 40 years.

I have developed an ingenious way of keeping my sinuses moist. I saved a plastic spray bottle of saline solution. After cleaning it out, I filled it with boiled tap water to spray up my nostrils, anytime, they feel dry. I use the spray



especially in winter when the house is dry. [Note: Recipe for saline solution: Pour 2 cups boiled tap water into a glass jar along with 1 teaspoon salt and 1/8 teaspoon baking soda. Mix thoroughly.]

*Brother Gerald Hickey
Highland Heights, OH*

When I fill up my Helios too much and it freezes up, I simply put it in the sink and run hot water. Everything will be thaw out and you'll be ready to go in about 30 seconds.

*Ann Tavares
Swansea, MA*



For many years, I have feared the tubing from my concentrator to my chair and bed. Three people I know have fallen as a result of getting tangled in the tubing.

The inexpensive Bayco Kord Manager has tamed my tubing and prevented it from pooling on the floor with kinks and twists. It can be found at hardware stores and on the Internet. The company also makes a retractable reel.

*Billie Humphreys
Sparks, NV*



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on how you COPE with COPD!
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If you know anyone who has been diagnosed with lung cancer, they can understandably feel overwhelmed. The National Lung Cancer Partnership offers a free booklet to answer initial questions often asked, called *Living With a Diagnosis of Lung Cancer*. To download the booklet and see other lung cancer resources, visit www.nationallungcancerpartnership.org on the Internet or call 1-608.233.7905.



Stretch your dollar tip - I have been using Breathe Rite Strips for about three years. I can cut the strips in half and they still work just as good!

*James Murray
Milford, IA*

I have COPD and am mucus bound. I could fill a bath tub! It is a killer at night. I cough and breathe like it is my last. I sit up for ten minutes and then go back to bed. I would like store personnel and

sheriffs to do more spot checks of the disability parking spots. I see many people who are not disabled parking in them. I carry a letter from my doctor with me.



*John Burdick
Corinth, NY*

Poetry Corner

Best One?

Pulmonary Rehab

Pulmonary Rehab is the place to go when your oxygen level is getting low.

There you'll meet others too who also have problems with their O2.

You'll learn a lot of different ways to help yourself cope with various days.

Days when the humidity makes it hard to just go out and get in your car

Or maybe a day there's a smog alert that makes your lungs feel like they're going berserk!

But the best part of going to Rehab is the people you'll meet and the fun you'll have For they too must struggle with each breath

They haven't given up - they live with zest!

Come join us in our fight to breathe with exercise, humor and living with ease!

Martha Ureke, Acworth, GA

Morning

Today I must start early, I'm going out at ten. I turn up the liters and fill the reservoir again.

Because the air is dry, I started a sinus rinse I notice that my nose feels much better since.

Time to get a fresh tank of oxygen to use Still check directions for those helpful clues.

Sniff the inhaler to keep my airways clear. All this takes time. I'm running late, I fear.

Now pack the oxygen in my walker pouch, Already feeling weary, I sink on the couch.

I look at the clock, nine thirty and I'm stressed.

My nose and lungs are ready But I still must get dressed!

Eleanor Hoppe,
Albuquerque, NM

A question we are often asked is "Which is better, taking your medication using a metered dose inhaler or by nebulizer?" The May 2007 *American Journal of Medicine* may have the answer - both!

Researchers studied 140 people with COPD over the age of 50 that were divided into three groups - those that used a metered dose inhaler, those who used a nebulizer and those that used both. People who used nebulizer therapy in the morning and at night and also used an inhaler during the day, had the most significant improvements in quality of life (as indicated by answers to questionnaires.) The best of both worlds - symptom relief from the nebulizer with the convenience of using an inhaler away from home.




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Men vs Women

Researchers have confirmed that the toll of Chronic Obstructive Pulmonary Disease (COPD) is harder on women than men, both clinically and physiologically. Why this is so, remains a mystery, according to the *American Journal of Respiratory and Critical Care Medicine*. The records of over 1,000 patients who participated in the National Emphysema Treatment Trial that evaluated Lung Volume Reduction Surgery were studied.

Women at the same advanced stages of COPD reported greater breathlessness and depression than men did. The distribution of emphysema in the lungs also differed significantly.



Women had significantly shorter smoking histories, were younger, had lower body mass index and decreased exercise capacity on the six-

minute walk test compared with men.

Depression and difficult breathing symptoms were higher among women.

In the year 2000, the number of women who succumbed to COPD surpassed the number of men. Further research into the differences between the sexes will need to be investigated.



In another study, *The New England Journal of Medicine* reports that breathing polluted air is especially dangerous to women between 50 and 79 years old. The study involved 26 US metropolitan areas and almost 66,000 women. It is thought that the small particles in smog travel deep into the lungs to cause inflammation which lead to heart attacks and strokes.

Membership Application to The Pulmonary Paper ^{18/4}

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Respiratory News

According to the *Journal of Applied Physiology*, if you are trying to lose weight, you can take a break! A team of researchers found when men exercised for two 30-minute stretches, taking a 20-minute rest break in between, they burned more fat than when they exercised for a single 60-minute session.

Be nice and calm! *Health Psychology* recently concluded the more hostile a young adult was, the more lung function declined. For each one-fifth increase in scores on the hostility questionnaire, there was a corresponding decrease in scores on the breathing tests. Hostility has already been shown to increase the risk of coronary artery disease.



Researchers reported in the medical journal *CHEST* that changes in atmospheric pressure, which often occur during storms, may be related to an increase in people suffering a collapsed lung.

Why do some people with COPD take their medications exactly as their doctor prescribed, while others do not? Australian researchers tried to find out in a study also published in *CHEST*. Those who did not take their medicines frequently said, "I vary my recommended management based on how I am feeling" and "I get confused about my medications." Patients' acceptance and knowledge about their disease and faith in the treatment were important factors if they were adhering to their drug therapy.