The Pulmonary Paper

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Dedicated to Respiratory Health Care

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Santa Is Shocked!

Also inside:

CFC MDIs Fade Away

Calling Dr. Bauer

Sharing the Health

The Pulmonary Paper

News Magazine

Volume 19, No. 6

November/December 2008

On the cover: Nick Jones of The Villages, FL, can't believe the changes in O_2 reimbursement.

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Santa, Santa, Santa!
Now who's naughty or nice?!

> **"Celebrate the happiness that friends are always giving, make every day a holiday and celebrate just living!"** **– Amanda Bradley**

***The Pulmonary Paper* Staff**

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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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November is a big month for promoting COPD Awareness, World COPD Day and the Great American Smokeout. On average, more people succumb every day from COPD (348), than diabetes (206) or breast cancer (114). There are an average of 750,000 hospitalizations for COPD every year with $37 *billion* spent because of the disease. This should warrant some attention and research dollars! We are thankful this holiday season for the progress we have made and look forward to continuing our mission of educating the public on what Chronic Obstructive Pulmonary Disease is all about. Thank you for your continued support. We wish you a healthy and happy holiday!

Celeste

Just the Facts!

Medicare Payments for Oxygen Concentrators

The oxygen user ***will not*** assume ownership of his or her concentrator. Beginning January 1, 2009, payments for your concentrator from Medicare to your oxygen provider ***will*** stop after 36 months.

Your supplier will continue to be responsible to service your equipment–for example, changing the filters and checking the flow output.

The supplier will be available for emergencies at any time of the day or night, even after their payments have stopped. (Though they may only bill Medicare for one visit every six months.)

After a five-year period, you may elect to receive new equipment, which would restart the payment period. If you do not choose to receive new equipment, the provider no longer has to service you.

The supplier will continue to provide your portable oxygen. It will be covered as a flat amount that may or may not cover actual costs.

What is not known as we go to print, is if Medicare is going to pay for travel oxygen, your cannula, tubing and other disposable supplies after they stop concentrator payments to your supplier.

Suppliers may elect to become “non-participating” providers on January 1, 2009, so they may bill oxygen users directly. You would pay their bill and then submit and accept the reimbursement Medicare will pay. Your provider’s costs of doing business may exceed the reimbursement.

Laurence Wilson, The Center for Medicare and Medicaid Services’s director of chronic care policy group, has said providers can’t just switch patients from one oxygen modality to another at their free will. He has received several calls from beneficiaries in Arizona who said their oxygen providers told them that Medicare would no longer cover liquid oxygen and they had to switch them to concentrators. “That’s untrue and it’s illegal,” said Wilson. “We are going to address those situations, continue to monitor them and take corrective action.”

Say Goodbye to CFC MDIs

As a reminder, the time to say goodbye to CFC (chlorofluorocarbon) propelled metered dose inhalers (MDI) is here. After the last day of 2008, your pharmacy will no longer be allowed to dispense the inhalers that are thought to harm the earth’s ozone layer. They are being replaced by hydrofluoroalkane (HFA) inhalers. (AeroBid, Azmacort, Metaprel or Alupent and Combivent hold an essential use exemption until Dec. 31, 2009.) You will need a new prescription for an HFA inhaler.

You will probably notice the HFA inhalers have a softer, warmer spray delivered with less of a force than you are used to. When used without a spacer/valved holding chamber, the HFA MDI should be placed directly in the mouth because of the softer spray.

After you thoroughly shake the HFA inhaler, it needs to be primed (releasing a spray into the air) according to directions and cleaned frequently to ensure that it is working properly.

If your physician has ordered Albuterol for you in the form of a ProAir HFA inhaler, you may receive $20 off each of your next five prescriptions by visiting www.proairhfa.com or calling 1-866-296-1401. This MDI should initially be primed three times and after two weeks of disuse.

For those on ProventilHFA, visit www.proventilhfa.com or call 1-800-750-9835 for instructions to receive a transition kit for a free inhaler and $15 off your next two prescriptions. You should initially prime this MDI four times and twice after four days of not using it.

If you use Ventolin HFA, visit www.ventolinhfa.com to print a coupon for $15 off four prescriptions per year. The Ventolin inhaler also has a built-in dose counter. Prime it four times initially and four times after two weeks of disuse. It should be discarded two months after opening.

The Xoponex HFA should be primed four times after opening and three days of disuse.

Corticosteroid and Long-Acting Bronchodilator HFA Inhalers are primed as follows:

- Advair: four times when opened and twice after four weeks of disuse
- Flovent: four times when opened and once after seven days of disuse or if dropped
- Symbicort: twice when opened; and twice after seven days of disuse or if dropped
- Qvar: twice when opened and after ten days of disuse

If you have questions about the transition from CFC inhalers, call the MDI transition team at 1-800-315-8056.

Calling Dr. Bauer …


Dr. Michael Bauer

For a comparison chart on room air cleaners, visit www.natlallergy.com/article.asp?ai=172&eid=INTSTF

Dear Dr. Bauer,

I'm considering installing a new heating system in my home and am wondering if a UV or electronic air cleaner would be beneficial to me or is it a waste of money.

BK, Las Vegas, NV

Air purification systems are likely to help those with allergy/asthma breathing problems rather that those who have COPD/emphysema. Although manufacturers make many claims, there is little scientific proof that air purifiers are helpful.

Electrostatic precipitators are the most heavily promoted purifiers. They use electric charges to trap particles onto filters. They should be used with extreme caution since these devices may emit ozone, a potent respiratory irritant. Never buy an air purifier that is classified as an "ozone generator."

Air filtering systems are the best for trapping dust, pollens and smoke indoors. High efficiency particulate (HEPA) filters are especially helpful and are thought to be more effective.

If you have forced air heating, a whole home air purification system is preferable over individual room air cleaners. A whole home system should be professionally installed.

Before you spend hard earned dollars on an air purification system, the American Lung Association recommends less expensive options. These would include banning indoor smoking, keeping pets out of bedrooms, removal of old carpeting, opening windows when possible and use of outdoor venting systems in the bathroom and kitchen.

I hope this information has been helpful to you and I sincerely wish that you and all our *Pulmonary Paper* members find peace and joy in this upcoming holiday season!

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

A recent lecture at the American College of Chest Physicians conference discussed a theory that Idiopathic Pulmonary Fibrosis (IPF) is caused by a repeated stimulus to the lung which results in injury. The injured lung does not heal properly and fibrosis or scarring occurs. The part of the lung that is fibrotic can not expand to take a deep breath or participate in the exchange of carbon dioxide and oxygen. People who have a "vulnerable lung" and/or predisposing genetic factors are often the victims of IPF. Smokers and those with rheumatoid arthritis are more likely to have the disease.

Current clinical trials will compare people with early stage IPF who take azathioprine (an immunosuppressant), prednisone (a corticosteroid) and N-acetyl cysteine (NAC) to those who take NAC only and to those who are given a placebo. NAC is an amino acid that serves as a precursor for the synthesis of glutathione, a detoxifying agent in the body. If treatment groups are no better than giving a placebo, we can stop giving the medications which are known to have many side effects. Another study involving people with moderate to severe IPF will compare people who take sildenafil (Viagra) or a placebo. Physicians are researching giving Warfarin (Coumadin) in addition to corticosteroids to see if it will be beneficial in IPF. Using DNA chips, University of Pittsburgh scientists plan to examine the activity of people's genes to find out more about the links in two of the most common cigarette-associated lung diseases: COPD and IPF.

We now only have supportive therapy, not curative. Scientists are working to find out what causes an acute exacerbation (worsening of the disease), why is smoking such a risk factor and why does IPF develop after the person stops smoking? We do know collapse of airways with abnormal re-expansion results in fibrosis. We know fibrosis is related to aging and those with IPF have shortened telomeres (DNA at the end of chromosomes which protect the cells from destruction). Your physicians are anxiously awaiting the latest news to help you!

A University of Pittsburgh team is the first to receive approximately $3 million in federal money to use "biochip" technology to study different smoking related chronic lung diseases. Using DNA chips, Pitt scientists plan to examine the activity of people's genes to find out more about genetic links in COPD and IPF.

"This study will help us understand why one person responds to cigarette smoke by developing emphysema while another develops fibrosis, and then to rapidly translate this knowledge from bench to bedside," said Dr. Naftali Kaminski, director of Pitt's Dorothy P. and Richard P. Simmons Center for Interstitial Lung Diseases.

Ask Mark …

Mark Mangus, RRT
EFFORTS Board

We would like to congratulate Mark on receiving the honor of becoming a Fellow of the American Association for Respiratory Care. A fellowship is conferred upon those who have met a standard of excellence in their practice. We thank Mark for his unending and unconditional support of people with chronic lung disease.

"Thorough testing has proved that my pulse oximeter reading is higher with continuous flow. Perhaps it would be a good idea to suggest that people get readings on continuous oxygen before recommending pulse flow!" Diz, Internet

Mark replies, "I definitely agree people should be tested with different delivery systems of oxygen to determine what is best for them! It seems that every time I write or speak about the comparison of pulse dose oxygen to continuous flow, controversy is sparked among those who insist that continuous flow is always and some how inherently better than any and all forms of pulse dose oxygen!"

Setting the same flow "number" from one pulse dose device to another and on a continuous flow meter will produce as many different results in terms of comparability as there are numbers of devices. When you want to achieve a specific saturation, regardless of the setting number, you will find that most devices can achieve this, when compared to continuous flow.

Oxygen conserving devices (OCD) vary according to the amount of oxygen delivered with each pulse, maximum respiratory frequency response rate, where within the inspiration the pulse is placed and how it is delivered. With so many variables and more than 30 devices on the market, a lot of information is necessary to understand any given device. Everyone should be set according to the results of titrating oxgen, using pulse oximetry during walking and other activities, to achieve a target saturation. The settings on a conserver will undoubtedly be quite different from those on the continuous flow meter. This should be no surprise since the numbers on the OCD do not translate into the same numbers on continuous flow meters.

Knowing how the OCD works is very helpful to understanding how to best use it to your advantage."

Mark adds, "You can also rest assured of your safety using sufficient oxygen to keep your saturation up in the mid 90s (normal) range without any fear of causing yourself to become a carbon dioxide retainer, much less have any tendency to breathe less or less efficiently when your saturation is in that normal range."

Also in our last issue, we apologize that we included outdated information we had in our Mark Mangus files about the Medicare age limit for lung transplants. People past the age of 65 do receive transplants paid for by Medicare.

Robert from California asks, "Is a lobectomy (removal of one lobe of a lung) the same as Lung Volume Reduction Surgery – LVRS?"

Mark answers, "Technically, the two procedures are not the same, though the effect can be the same. If you take out a part of the lung as large as a lobe, it will reduce total lung volume and create space into which remaining lung may shift. With LVRS, the surgeons clamp across a portion of the lobe and cut it out. A lobectomy tended to result in removal of too much tissue. The purpose of LVRS is not as much to remove diseased tissue (though, that is a primary objective) as it is to allow shifting of the diaphragm to a more normal position. This helps position it to generate more force with less effort/energy. In the process, more functional tissue shifts into the space made by removing the diseased tissue.

I don't know that there is a hard and fast cut-off age for LVRS. Usually, they want the FEV-1 (Forced Expiratory Volume in one second) to be under 30% of predicted. More important, the total lung volume must be at least 130% of predicted, since the goal is to reduce the lung volume by 30%. Your emphysema must be concentrated in the area to be cut out, with most of the rest of the lungs functioning as close to normal.

Mark Mangus RRT, BSRC, is a member of the Medical Board of EFFORTS (the online support group, Emphysema Foundation For Our Right To Survive, www.emphysema.net). He generously donates his time to answer members' questions.

Feelings

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

Robert and Peg Riley of Ohio want to share their secrets of living with COPD. Bob says, "At first, I thought everything I loved was over. Then I decided I would set small goals and increase them a little every day. I realized the more I sat, the sooner I would become an invalid. I was never going to let the illness define me or my life. I was not going to just deal with the disease and survive."

In 1998, Robert's physician told Peg if she wanted to have their dream of traveling the US come true, she should quit her job and get started. The couple visited the entire continental US, Alaska, all the Canadian provinces plus two trips to Mexico. "We enjoy an active retirement, living a life affected, but not controlled by my COPD. Health professionals treat COPD, but it is the patient who must manage it!" commented Bob.

Peg writes, "As a COPD caregiver, one must adapt to the various physical (air conditioning so low I need a coat), emotional (short tempered, particularly when on Prednisone) and environmental (cooking different foods causes him breathing problems) needs and limitations. You must leave functions early or never get there in the first place. You must remain calm and reassuring at all times. You may feel like you are providing support, they may think you are nagging. You may feel isolated and under-appreciated. You should focus on what you can do with the person; not what they can no longer do. Be aware that the complexity of medicine requires additional support. The person with COPD must accept and respect that you are their advocate. Carry an updated medical history. Go along on office visits. Have names, addresses and phone numbers of doctors, therapists, pharmacists and your insurance card. Keep a list of current medications and know why each one is being given. Don't be afraid to ask health care personnel if they have washed their hands! Physicians of today recognize that having another pair of ears and indeed another mouth can make a difference!

I have Alpha-1 antitrypsin genetic COPD. I am on oxygen 24/7. I have also been on the transplant list since 2003. I cope with COPD by staying positive and working out three days a week and never giving up! Faith in the Lord and a strong wife by my side keep me going. Knowing God is with me through these challenges, I'll never give up!

James Rader

Sharing the Health

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.

You have to keep it light! Last night my wife and I were out to dinner when six other folks (all strangers) walked in at were seated a few tables away. One was carrying a Helios liquid oxygen device. As they passed by, I yelled, “Hey, Airhead!” He and his wife turned and noted that I was wearing the same device. I went over to their table and announced to the group, “Now I want all of you to understand that whenever this fellow says or does something stupid, it is due to oxygen deprivation and he is to be excused immediately!” They all roared in laughter. I told them how, when my wife was upset with me at home, she would wait for me to begin to walk away and then step on my oxygen hose, nearly ripping my ears off. His wife thanked me for putting her “in the know.” The couple will be in attendance at our next Airheads support group meeting, already trained to answer, “Great!” when asked how they are doing.

‘Santa Cover Boy,’ Nick Jones, The Villages, FL

In the last newsletter, I saw the recommendation to carry a small basket with your medications for convenience. I have found that the clear, plastic, fishing lure boxes–found in the fishing sections of sporting good stores–work well. They can be found in various sizes; they are light and waterproof. Prices vary with size.

I also have a blog in which I write a mixture of humor and editorials. Now that I am on oxygen, I try to keep my nose dry. I don’t want a run in my hose. Please visit http://ramblersteveganshert.blogspot.com/

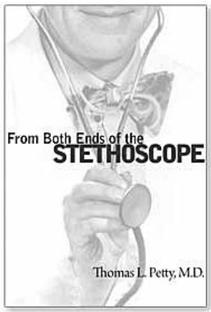
Steve Ganshert, Sartell, MN

I make homemade “Hamburg Soup” and keep small containers in the freezer for those days that I am not feeling so well. I am getting a nutritional meal with the vegetables, meat and broth!

Carmen Parent, Orono, ME

I finally understand my COPD after reading ‘COPD for Dummies’ by Dr. Kevin Felner. Knowing I need to increase my intake of vegetables, I’ve tried to keep fresh or frozen on hand, but they seem to go bad quickly. I checked out the latest in prepared baby foods. Their vegetables are low calories, low fat and not bad tasting!

N. Lofton, Johnson City, IL

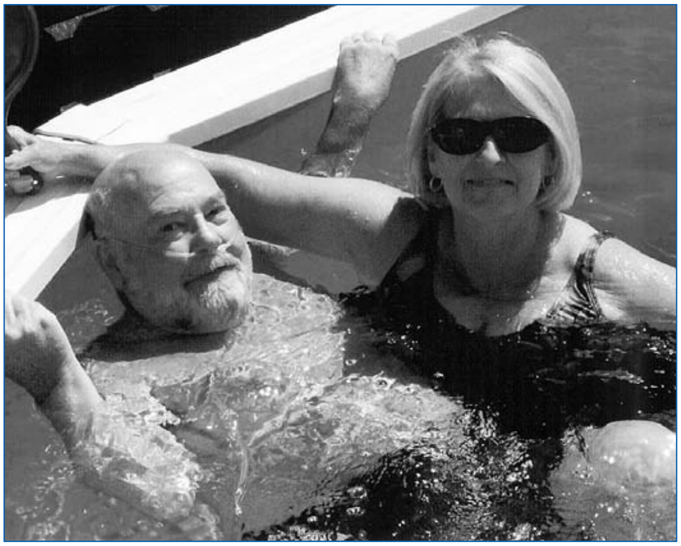


Dr. Tom Petty played a very important role in establishing pulmonary rehabilitation and the use of supplemental oxygen in this country. His medical journey started in 1954 and continues today with Dr. Petty using oxygen himself. He has written a new book, *From Both Ends of a Stethoscope*. Dr Petty tells of his experiences and advises us how to survive with medicine today. To order a signed copy, email TLPdoc@aol.com, phone 1-303-996-0868 or send a check for $17 to: Thomas L. Petty, MD, 899 Logan St., Denver, CO 80203.

The American Respiratory Alliance of Pennsylvania is again offering its members a free washable, green foam mask to give you an extra layer of protection from the cold weather. You may visit their web site at www.healthylungs.org or call 800-220-1990. If you live outside of western Pennsylvania area, please send $5 for shipping and handling with your name and address to the American Respiratory Alliance, 201 Smith Drive, Ste. E, Cranberry Township, PA 16066.

Does anyone have any suggestions on finding friends who are willing to put up with your lung disease? Most of mine don’t want to be bothered with me. Is there something we can give them in return?

LL, Port St. Lucie, FL



I was diagnosed with Idiopathic Pulmonary Fibrosis in March of this year. I am always looking for ways to maintain my present level of health. I keep as active as possible and try to have fun doing it. Exercise is easier for me in the water and also when I have a partner!

Arnie and Terry Duckett, Akron, OH

We hope you participated in our recent elections. One of our own was right in the middle of the campaigns, not as a volunteer but as a write-in candidate to be a State Representative of the Twelfth Worcester District of Massachusetts. Unfortunately, Bill Higgins was not elected, but we could not be prouder of him!

Bill Higgins

I am oxygen 24/7 and use a nebulizer twice daily. Walking any distance before I've had my breathing treatment is very difficult. Brovana, the medicine I use, needs to be refrigerated. My children bought a small refrigerator for my bedroom. Now I can use my nebulizer upon awakening without struggling to get to my medicine!

Beryle Peck, Knightdale, NC

I bought my husband a mattress wedge – it really helps with his shortness of breath at night!

PR, OH

My tip is "What works for me may not work for you!" It is why, at last count, there are 1,538 cold remedies on the shelves of pharmacies. If the retailers are trying to keep us old folks confused, it often works! I have learned patience through aging (and having COPD) and continue to live and learn through listening and reading, mostly to people who have COPD!

Jackie Nieter, South Bend, IN

Tai Chi and *Fit Steps for Life* walking program are low impact forms of exercise that build strength, increase flexibility and improve balance. When I had to go for a heart bypass operation, I was able to recover much quicker because of the strength of my muscles. Exercise and a balanced diet are the key ingredients for a quick recovery!

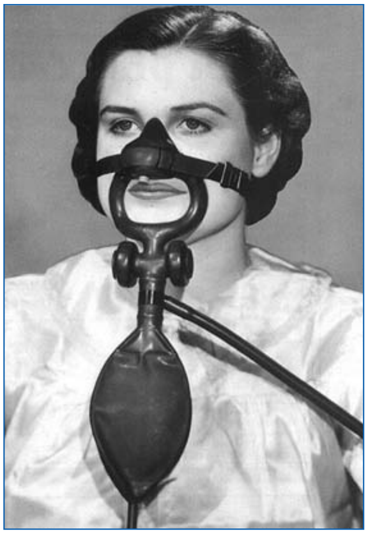
Barry Jacobs, Tyler, TX

Traveling Tales

Masks Solution to O_2 Pressure Drop in 1930s

At a party in 1937, the president of Northwest Airlines told Dr. Charles Mayo, son of one of the founders of the Mayo Clinic, about a recurring health problem among his pilots. They would become drowsy while flying at 13,000 feet or higher over the Rocky Mountains. Dr. Mayo began a study and devised a mask which mixed air and pure oxygen. It solved the problem for the pilots flying as high as 40,000 feet. Northwest became the first U.S. airline to install individual outlets for passengers as well.

In the 1940s, prior to pressurized aircrafts, all passengers wore oxygen masks. As you gain altitude, the driving pressure of oxygen changes, even though the percentage stays the same. At sea level, it is 14.7 pounds per square inch or psi. At 40,000 feet, it is 2.7 psi. Today, cabin pressure is maintained at no greater than 8,000 feet.



Luckily, we have come a long way from the first oxygen mask. A sixth portable oxygen concentrator (POC) may be used during flight when the FAA approves the XPO2™ from Invacare®; the approval is expected by the end of the year. Starting in May 2009, all airlines must allow the approved POCs on all flights originating or ending in the United States.

If you are requesting oxygen from the airlines, be sure to specify a nasal cannula or you may end up with a mask, which many feel is uncomfortable to wear.

Ready to Roll!

Happy holidays, everyone!

Product Corner

Eagle Respiratory Solutions, LLC markets a shoulder bag to carry liquid oxygen portables up to size D tanks. The creator of the Freedom Sling, Joe Walsh, says he is first and foremost a patient with IPF (Idiopathic Pulmonary Fibrosis). Out of necessity to free up his hands, Joe devised the oxygen carrier. Joe says, "Just because people use oxygen, it does not mean they have to be confined to their house." He wants everyone to enjoy the sun, talk with others and bring back some of the laughter that we had prior to our diagnosis. Joe says, "Laughter is 20 percent funny and 80 percent healing!"

The Freedom Sling is ergonomically designed to be worn over your right shoulder. The sling slips on and off easily, which is beneficial for people with joint problems. The carrier's "wing design" allows for the entire weight of an oxygen unit to be evenly and confortably distributed along your whole back. Freedom Sling is adjustable and has multiple pockets for storage. It has quick release buckles that can be removed quickly or may be converted from a medical oxygen pack to a secure shoulder bag for a more accelerated activity like golf, biking or working around the yard. The sling comes in royal blue, black and tan. For more information, visit www.freedomsling.com or call 1-720-941-6212. If you would like to order the carrier on the Internet, you will receive a 20 percent discount off the $129.99 price if you enter coupon code–HEALTH–until January 15, 2009. If ordering by phone, be sure to tell the representative you are a member of *The Pulmonary Paper* to receive the discount.

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Respiratory News

A proposal to give the Food and Drug Administration (FDA) the power to regulate tobacco products appears dead for the year, but anti-smoking advocates say they expect it to pass in 2009. The measure passed the House this summer with overwhelming support, but a threat from Sen. Richard Burr from North Carolina to block it and a veto threat from the White House helped stall it in the Senate. President-elect Barack Obama strongly supports giving the FDA the authority to restrict tobacco marketing and set standards for nicotine levels in cigarettes.

COPD Update

The various lecturers at recent meetings told us:

- Antibiotics have not been proven to improve pulmonary function and quality of life in people with COPD. But antibiotics, along with long-acting bronchodilators, inhaled steroids, lung volume reduction surgery and the influenza vaccine have reduced exacerbations in COPD.
- Advair 250/50 significantly reduced the rate of moderate to severe exacerbations. Combining Spiriva with Advair has been shown to decrease hospitalizations. Smoking cessation is the main intervention that has been shown to prevent lung function decline.
- Despite what one published study reported, Spiriva is not associated with increased cardiac complications or overall mortality.

If you would like to have ammunition to spread the word, the COPD Foundation and the National Heart Lung and Blood Institute (NHLBI) have created an advocacy kit-in-a-box. Inside this box you will find a guide on how to use the handouts with general information about COPD, life resource cards, a DVD interviewing people that cope with COPD and a CD with radio and tv Public Service Announcements. The kit is free, the only cost is $8.50 for shipping. Call 1-866-316-2673 or visit www.LearnAboutCOPD.org to order the kit and download many other resources to raise awareness of the fourth leading cause of death in the United States. If you would like to order multiple copies of the kit, please call the Health Information Center at 1-301-592-8573.