Second Wind
NEWSLETTER

AUGUST-SEPTEMBER 2003

PERF, the Pulmonary Education and Research Foundation, is a small but vigorous non-profit foundation. We are dedicated to providing help, and general information for those with chronic respiratory disease through education, research, and information. This publication is one of the ways we do that. The Second Wind is not intended to be used for, or relied upon, as specific advice in any given case. Prior to initiating or changing any course of treatment based on the information you find here, it is essential that you consult with your physician. We hope you find this newsletter of interest and of help.

Influenza, Nonin oximeter, Dr. Petty's oxygen book, Cruising with oxygen in 1984, Competitive bidding for oxygen, Medicare payment for Lung Volume Reduction Surgery

August is behind us but we are still sweltering in the hot and humid dogs days so typical of that month. We *should* be writing about how to handle the heat, though it is a little late for that. Since there will be no September newsletter We have some important reminders for you. Flu season will soon be upon us and we want all of you to be protected. Don't forget to wash your hands frequently! Have you heard why, in the middle of the SARS outbreak, Japan alone of all the Far East countries, was spared? It is speculated that it was frequent hand washing, for which the Japanese are noted, that spared them the ravages of this terrible virus. Remember that, and go and do likewise! Hand washing is one of your best protections against colds and other viruses. And for even more information, we are pleased to provide you with the following article.

Influenza, the Killer "Flu"

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What is influenza?

Influenza is a virus that causes infections in humans as well as in a variety of birds and mammals. There are two main circulating types of influenza, influenza A and influenza B. Influenza A causes much more severe illness than influenza B.

Is influenza the same as "the flu"?

Influenza *is* the same thing as "the flu". Unfortunately, the word "flu" is commonly used colloquially for describing a variety of maladies such as colds (which are caused mainly by rhinoviruses, not influenza viruses) and the stomach "flu" (caused by viruses unrelated to influenza). Neither of these infections are

technically "the flu". This broad use of the word "flu" is very unfortunate because it softens most people's perception of how serious influenza is. Colds and "stomach flus" are typically self-resolving infections that are mildly incapacitating, at worst. ***Influenza however, kills tens of thousands of Americans annually.***

Influenza, the killer

Worldwide it is estimated that influenza kills 250,000 to 500,000 persons each year. These deaths occur primarily in elderly patients who live in industrialized countries. Because influenza is transmitted easily from person to person through sneezing and coughing, global spread of the virus during the winter occurs annually. Particularly bad outbreaks occurred in 1918 (the "Spanish flu"), which killed as many as 50 million persons worldwide. Other severe outbreaks occurred in 1957 ("Asian influenza") and 1968 ("Hong Kong influenza"). While many persons are currently concerned about SARS, only a relatively small number of persons worldwide have died of this infection, none in the United States. For most people, influenza poses far more of a serious threat to their health than SARS, at the present time.

Symptoms of influenza

Influenza infection is characterized by sudden onset of high fever (typically greater than 101.5°F), muscle and head aches, severe malaise, non-productive cough, sore throat, and runny nose. In other words, it is like a very bad cold with a high fever and severe aches. For those patients who have had it, the infection is usually very memorable for the significant amount of disability it causes, much more so than a cold. Although most people recover within 1-2 weeks without requiring any medical treatment, in the very young, the elderly and people suffering from medical conditions such as chronic lung disease, diabetes, cancer, or heart problems, influenza poses a serious risk. In these people, infection may lead to severe complications of underlying diseases, pneumonia, and death.

Influenza vaccines

Unfortunately, influenza is a master of change. Each year, the predominant influenza strain differs from the previous year. Each year scientists survey influenza activity worldwide to determine which influenza strains are most likely to circulate in the coming winter. Vaccines are then rapidly produced to prevent the likely invading strains. Most years the predominant circulating strain is successfully predicted. **Influenza vaccine must be administered annually as each year's vaccine differs from the previous year's.** Vaccines are given by injection, which typically become available in September or October. Persons who should be vaccinated annually include elderly persons, health care workers, and persons of any age who are considered at "high risk" for influenza-related complications due to underlying health conditions. This includes patients with chronic lung and heart disease. Recently, vaccination of children has been encouraged in the United States.

A new intranasal (nose spray) flu vaccine was approved in the United States in June 2003. It differs from the injection vaccine in that it uses a *live* virus rather than a killed

virus. It should *not* be given to persons with poor immune function such as AIDS and cancer. **It may also transiently exacerbate symptoms of asthma or reactive airway disease and should not be given to person with these conditions.** Finally, both vaccines should not be given to persons with allergies to eggs or previous influenza vaccines.

"I had a flu shot before and it gave me the flu"

Physicians and nurses often hear this after offering a flu shot to a patient. This belief probably stems from many persons incomplete understanding of what the flu or influenza really is (again, it's not a cold). People typically get vaccinated during cold (and influenza) season and flu vaccines will *not* prevent colds. Several investigations have actually addressed this issue and found that persons getting flu shots were no more likely to get colds than persons administered a "dummy" (placebo) flu shot of saline (Nichol KL et al. Arch Intern Med 1996;156:1546 and Margolis KL et al. JAMA 1990;264:1139). Persons who got flu shots did have more soreness around the injection site than those given the placebo shots.

Antibiotics for the flu?

Commonly prescribed antibiotics do not work against the flu, however there are specific antiviral antibiotics that have activity against influenza virus. These antivirals include amantadine, rimantadine, oseltamavir, and zanamavir. All come in pill form except zanamavir, an inhaler antiviral that should *not* be administered to most persons with chronic lung disease. Antivirals modestly minimize or shorten the duration of influenza symptoms, but have to be given within 48 hours of symptom onset or they will have little to no effect on the infection. Some of these antivirals are also approved to prevent infection among persons who have been exposed to influenza but have not yet come down with symptoms.

Where can I get more information on the flu?
The World Health Organization:http://www.who.int/entity/csr/disease/influenza/en

Thank you Dr. Miller for this informative article! While many doctors' offices do not get their flu vaccine until October, it is a good idea to call now and make your appointment well in advance. Our thanks again to Dr. Miller for all of this valuable information!

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Bill and Shirley Grindrod of Anaheim, CA have made another donation to the Chair. Bill and Nancy Gibson made a donation to PERF. Thanks, folks.

***Jinny von Goerlitz** died last week after a long illness. Her husband, Ted, kept us apprised of her valiant struggle. Ted credits Jinny's pulmonary rehabilitation program for her more than ten years of high quality life. Memorial donations to the Chair and PERF were made by Dr. Rich Casaburi, Mary Burns and Elaine Von Goerlitz in memory of Jinny von Goerlitz.*

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News About the Nonin Oximeter
Those of you who sent in an e-mail to subscribe@perf2ndwind.org will have gotten this news a few days after your last newsletter arrived but we want to repeat it here for those of you who are not on line.

Mea Culpa from Mary: corrections and updates.
In last month's newsletter, we left out the last digit of the phone number of the Richmark Company. The correct number is **1-800-882-8889.**

In calling back the REI Sport stores, after talking to several clerks, we found the cause of confusion. The number 643-382-0013 is the **order number** for the SportStat in the REI Store. It is **not** a telephone number that you can call if you don't have an REI in your area! You can however, go to their website at www.rei.com and type SportStat in the Search box to place your order or get information.

*The best news, and update, however, came from **Aeromedix***. They are offering our readers a special discount **of only $340.00** on the **$395.00 Nonin 9500 Onyx Oximeter.** This is the medical oximeter with all the pertinent information included, and the best offer we have been able to find. To be eligible for this discount, tell the person taking your order that you know that the regular price is $395.00. Identify yourself as a reader of the Second Wind, or of our website, and ask for the discount price of **$340.00**. If you are ordering through their website write this in the remarks box. Shipping costs an additional $7.00 to $9.00 for UPS 3 Day Service, depending on your location. Sales tax applies *only* to orders shipped to the state of Wyoming.

Aerometrix has doctors on staff. They are able to take care of the oximeter prescription for callers, as well as answer any medical questions. There is no charge for this courtesy. This makes it much easier for the patient to get the **Nonin 9500 Onyx** without the hassle of getting a prescription from his or her own physician. They can't give a diagnosis over the phone of course, but this allows you to get the medical oximeter sent out that same day.

For their web link, use www.aeromedixrx.com as **this is their pharmacy site for the 9500 Onyx** and other prescription pulse oximeters. They told us again they are *not* allowed to recommend the FlightStat for medical purposes. It is sold over their web site to pilots and other recreational users.

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Here is still more news about Nonin, and why we are sending them our thanks.

This September 20th, Mary Burns will be accompanying a group from Harbor-UCLA when they visit **Szeged University in Hungary.** The visit was arranged by **Attila Somfay, MD, PhD**, the Chief Pulmonologist at the University and Hospital, who spent almost two years at Harbor-UCLA doing research. He is a good friend of us all and some of the research participants in the Rehabilitation Clinical Trials Center will remember him well.

While the docs are delivering lectures to the medical staff, Mary will be

having fun working with the therapists and patients at Deszk Hospital. After a slide show about pulmonary rehabilitation in the United States, she will work with the therapists to teach breathing techniques to their patients. That's where the Nonin comes in. While you certainly can learn proper breathing without an oximeter, it is a lot easier when you have feedback from the pulse oximeter right in front of you. Do you remember that with good breathing techniques you can actually *raise* the oxygen saturation of your blood and watch the saturation numbers climb on your oximeter? Perhaps even more important, you will see them *drop* with poor breathing techniques! Very impressive, and a lot more effective than having some nurse or therapist tell you what to do! The Nonin Company didn't just lend Mary an oximeter for the trip; they went one better. They *donated* the oximeter so that it can be left with the rehab team at Deszk Hospital. We have been told that the Deszk rehab unit doesn't have an oximeter so you can imagine how much they will appreciate this nifty gift.

So, is it going to be all work in Hungary? No way! With **Janos Porszasz MD, PhD, our PERF Webmaster**, leading the caravan, this group will get to see countryside, castles and cities. He promised us some gipsy music and good Hungarian food as we tour his former country. Besides Attila and Janos, others you may recognize in this group are PERF President Rich Casaburi and his lovely wife, Mary. Our Swedish researcher friend, Dr. Margareta Emtner and her husband Morgan, will be part of the two-car caravan. Do you remember the Second Wind issue last October dedicated to our visit in Upsala and the ERS (European Respiratory Society) Conference in Stockholm? This will be a reunion of the same group.

After six days in Hungary, we drive back to Vienna, Austria. The next five days will be busy ones at the ERS Conference. There, we will be joined by PERF Board member Dr. Brian Tiep, as well as many other friends from around the world. **Because of this trip, there will be no September newsletter**. Please notice how much information we have crammed into this one, however! In addition, we promise that the October newsletter will be about pulmonary rehab in Hungary as well cutting edge information we learn at the conference. Don't miss it!

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Dr. Tom Petty tells us that now that *he* is a user of oxygen, he has a different perspective than when he was studying and promoting Long Term Oxygen Therapy (LTOT). He asked us to send the following message out to all of you who might have contact with oxygen patients, or are on oxygen yourselves. *Spread the word!*

Dear Friends,

*Now that I am a consumer, I have gained additional perspective about LTOT (Long Term Oxygen Therapy). I decided to write a new book, "**Adventures of an Oxy-Phile**". I will cite the scientific basis for LTOT in appendices, but start with my own adventures, beginning with our first studies of ambulatory LTOT in 1965. I will then add my own vignettes "from the other end of the stethoscope."*

I hope you and your friends will contribute a one to two page anecdote of something funny, frustrating or especially interesting about LTOT, particularly when the use of oxygen allows work, travel or adventure. Please have these sent to NLHEP@aol.com by ***September 15th****.*

This should be fun to put together and will probably stimulate a lot of readership. Hopefully CMS (Center for Medicare & Medicaid Services) might also be interested.

I hope your summer is going well.
Best regards,
Tom Petty

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Memo from Mary**:** Have you thought of a story you would like to tell? There are so many anecdotes that I could relate about the use of oxygen that it was hard to decide which ones to send in for this book by Dr. Petty. Cruising is taken for granted these days. That pleases me, as I think back to the *many* problems we had to overcome in order to sail on that first cruise with oxygen users. Here are just a few of the amusing things that happened on that historic first trip.

Cruising With Oxygen

Did you know that back in 1984 medical oxygen was considered hazardous cargo, and not allowed on cruise ships? We didn't, when we naively planned our first cruise for oxygen patients. Three weeks before sailing, when we rechecked with the cruise line, we found to our horror that the tourist agency had told them nothing about our plans to take oxygen on board. The cruise was off. Our tourist agents, eager not to loose the commissions from our group of 50, encouraged us to "sneak on board", or "run past the ticket taker at the last minute". Visions of our patients running up gangways pulling their oxygen, pursued by ticket agents, were not what we had in mind for this dream trip!

After inundating them with safety information, *and* a powerful letter from Dr. Petty darkly hinting at the evils of discrimination, we finally convinced the reluctant Azure Seas to allow us on board with oxygen ***IF*** we could get Coast Guard approval! Everyone was sure we could never budge that bureaucracy. But, miracles really do happen, especially when you work very hard to achieve them. In a frantic three-week period, all obstacles were overcome. On June 11, 1984, we sailed from San Pedro, CA to Ensenada, Mexico. For the first time in history, passengers with oxygen were not only allowed on board a cruise ship, but also allowed to sail! Oxygen dependent passengers have been cruising ever since.

Wonderful things began to happen in that ocean air. Patients who had hated upper extremity exercises in pulmonary rehab classes would play the one armed bandits by the hour, with nary a complaint. Those who "couldn't" handle stairs at home, managed very nicely, with their portable oxygen, to climb the half flight up to the casino.

Back in those days, portable liquid oxygen wasn't very common. All of our patients, however, were supplied

with liquid portable systems for this trip. One of the other passengers, puzzled by the units pulled by our oxygen users, was heard to comment, “Look at all those little vacuum cleaners. This is the cleanest ship I’ve ever seen!”

One night at dinner, a white-faced steward anxiously hurried me and the other nurse, Maureen Finnerty, out of the dining room. He told us an oxygen unit was about to blow up, and the ship with it. Courageously, two stewards had dragged the unit to an outside deck while another had cordoned off that area of the ship. Maureen and I couldn’t suppress giggles as we beheld the steaming oxygen unit, attached to a frozen portable, surrounded by a pile of “snow”. Some hot water poured over the frozen connection remedied the problem caused by a patient, unaccustomed to using a liquid system. We complemented the men on their bravery, while reassuring them that hair driers would work next time if they didn’t want to get the carpet wet.

The frozen portable was one of a series of events caused by our problem patient. Though accompanied by his “girlfriend”, supposedly a nurse, he was always in some kind of mischief. He was a wiry little gnome of a man, probably smaller than 5’3”, with long white hair and a long, stringy white beard. His favorite trick was to hide behind a potted palm, sipping Bloody Marys, while checking out the ladies walking by. He liked ladies. Whether it was the Bloody Marys, or his love of ladies, we don’t know. But something prompted him to enter the ladies’ restroom when he “had to go”, as he put it later. Seconds after he snuck in, a shrieking, hysterical woman come tearing out. She tripped over the riser in front of the restroom door, almost falling in her haste to escape. She was babbling loudly about being invaded by a little space man with green tubes in his nose. (Did you know that oxygen tubes used to be green?) Our “space man” was confined to quarters until his “nurse” promised to make sure that all his beverages were non alcoholic and that he limited his rest room visits to those that said “Men” on the door.

Another amusing dinner episode occurred on our last night. Lights were lowered and waiter after waiter paraded in to the dining room, each carrying a flaming Baked Alaska to one table after another. Our group was last. Our Alaska’s got about 100 feet away, and then stopped long enough for everyone to admire, *if* they had good distance vision. The flames were carefully extinguished before the non-flaming Baked Alaska came any closer to our tables. We gave our waiters an extra large tip to compensate them for their “hazardous duty” in waiting on our tables.

How times and attitudes have change! What *hasn’t* changed is the fun people have when cruising. Some of our group found that oxygen was no deterrent to swimming, and learned to enjoy the pool. Others again discovered dancing. One of our group parked his portable oxygen on the deck and swung into Swing steps, joined by his gyrating wife. Their audience burst into appreciative applause.

Our entire group attended the Captain's Dinner Dance. They were resplendent in evening clothes and proudly posed, with their oxygen on, for the inevitable picture by the boat photographer. Who said being on oxygen was the end of a fun life? They didn't! They danced, carrying their own oxygen or having their partner carry it. It didn't matter; they were having fun! So, the next time those of you on oxygen go on a cruise, don't take it for granted. Remember the adventures of our pioneering group, way back in the dark ages of 1984, and enjoy!

Did this bring back memories of some of your experiences with oxygen? If so, write them down today and email your story to NHLEP@aol.com by September 15th.

Oxygen and Reimbursement: "A Most Important Issue"
Thomas L. Petty, MD

Oxygen is the only proven treatment for advanced stages of COPD that has been shown by first rate studies to increase both the length and quality of life and to reduce hospitalizations. Today a million Americans, most of whom have COPD, receive long term oxygen therapy (LTOT) in the home.

The specter of "competitive bidding" looms large and has already passed the House of Representatives. I hope it can be thwarted in the Senate. IF competitive bidding remains MODALITY NEUTRAL, this will be a disaster, because the new advances in ambulatory technology, which are naturally more expensive, will be threatened.

The reason is simple. Providing a stationary concentrator and an E-cylinder on wheels is cheaper. But this system inhibits ambulation and activities of daily living. The Nocturnal Oxygen Therapy Trial (NOTT) showed an improvement in survival and a reduction in hospitalizations for groups with an ambulatory system. These groups could do more exercise than groups limited by a stationary system.

Ambulatory oxygen has become the standard of care, as indicated in "Recommendations of the Fifth Oxygen Consensus Conference" (Respiratory Care, 2000, 45:957-961). This is undoubtedly the **most important issue facing any COPD group,** and NECA should be the standard bearer for this issue. [*NECA is the National Emphysema COPD Association*] It is an important part of the efforts of NECA, NLHEP, the National Lung Health Education Program, and others, to promote public awareness that COPD is a long standing and progressive chronic disease. We need to work together not only on early identification and intervention, but on the entire continuum, from asymptotic to late stage disease.

And what can you do about that? Read the following article for help.

COMPETITIVE BIDDING

WRITE YOUR CONGRESSMAN AND SENATORS TODAY!

We have received permission to reprint this excellent letter written by Jon Tiger, NHOPA President. NHOPA is the National Home Oxygen Patients Association. Readers who

wish to write or email their members of Congress regarding concerns related to competitive bidding for oxygen are encouraged to do so. NHOPA has told us that you should feel free to borrow from this letter written to House and Senate conferees on the topic:

The Congress is currently considering legislation that would, if the version approved by the House of Representatives prevailed, mandate competitive bidding for home oxygen currently provided as a Medicare benefit to approximately 800,000 Americans. We are fearful that such a move would have a seriously deleterious effect upon the availability of oxygen systems to Medicare beneficiaries for several reasons:

As we are sure you know, the Medicare payment methodology for oxygen is based upon a "modality neutral" model, thereby creating strong financial incentives to provide the cheapest oxygen equipment. Under a pure competitive bidding structure, ambulatory systems would become even less readily available, as indicated by the preliminary results of the current demonstration projects being conducted by Medicare in San Antonio, Texas and Polk County, Florida.

Medical evidence is accumulating that use of lightweight ambulatory oxygen is more effective in restoring vital functions than oxygen delivered by stationary systems. Both length and quality of life is increased and hospital use reduced by the use of ambulatory systems. [Editor's note: While not yet established, this is the subject of proposed research.]

With a system that encourages ambulation, patients are more active, one of the clear paths to a longer, more productive life. Obviously, the availability of such portable systems is vital for these patients, and we are fearful that a national program that is modeled after the current Medicare demonstrations would unquestionably be detrimental to the health of hundreds of thousands of Medicare beneficiaries.

An integral part of the Medicare benefit is the availability of professional medical support, usually provided by respiratory therapists. It is our understanding that this professional support has also virtually disappeared during the two Medicare demonstrations currently underway.

We strongly urge you to oppose any effort to mandate competitive bidding for home oxygen systems unless there are explicit requirements that would ensure the availability of the specific oxygen system requested by the prescribing physician and the resources of health professionals such as respiratory therapists and others who are trained in the area of chronic obstructive pulmonary disease, the primary diagnosis of supplementary oxygen patients.

We know that many of you remain interested in what the government has decided to do about payment for **Lung Volume Reduction surgery**. The California Thoracic Society (CTS) provided us with the following article taken from the New York Times.

Medicare to Pay for Major Lung Operation

N Y Times August 21, 2003
By DENISE GRADY

Medicare will begin paying for a major lung operation for certain people 65 and over who have severe emphysema with specific traits that make them likely to benefit from the surgery, the government announced yesterday.
The operation, lung volume reduction surgery, involves cutting away diseased parts of the lungs to help the remaining healthy tissue work better. As much as 30 percent of the lungs may be removed. The operation costs about $60,000. Private insurers and state Medicaid programs generally follow Medicare's example.

Medicare said yesterday that it would cover the operation for two groups of patients: those who have severe emphysema in the upper lobes of their lungs, and those who have both severe disease elsewhere in the lungs and a poor ability to exercise. In addition, such patients would need certain other test results to make sure they were not at high risk of dying from the surgery itself.

Medicare will also require that patients be given an extensive exercise and education program to improve lung function both before and after the surgery.

The operation will be covered only at certain hospitals accredited by the Centers for Medicare and Medicaid Services; the hospitals have not yet been named.

Two million Americans have emphysema, but only a small fraction - perhaps as few as 10,000, researchers say - would qualify for the surgery. The disease, which destroys the air sacs in the lungs, makes it increasingly harder to breathe. It is nearly always caused by smoking. Emphysema is incurable and often fatal, and it causes or contributes to 100,000 deaths a year in the United States. Caring for people with the disease costs more than $2.5 billion a year.

The decision to begin covering the lung reduction surgery is based on the findings of a government-sponsored study published in May in The New England Journal of Medicine. That study, called NETT, for National Emphysema Treatment Trial, found that in about 25 percent of participants, the operation improved both quality of life and length of survival. In others, it did not prolong life but did improve exercise capacity or overall quality of life. In an additional 30 percent, the operation was either too risky or simply did not help. Lung reduction surgery, developed in the last decade, quickly became popular even though, until recently, no large, rigorous studies had been done to find out whether it was safe or effective. Medicare initially paid for the surgery and then stopped, citing the lack of data. It then agreed to cover the procedure only in patients who enrolled in NETT, which started in 1996.

The insistence on rehab, before and after the surgery, is a positive step toward a more favorable reimbursement policy for those of you who wish pulmonary rehab without the surgery. Those of us who believe so strongly in rehab applaud this! Till next month, stay well. ♥♥♥