



# Second Wind

## NEWSLETTER


**FEBRUARY 2004**

*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 help.*

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Spiriva, Increasing oxygen levels without oxygen, PLB instead of oxygen, embarrassed using oxygen, Lung growth and exercise, Dr. Steven Reynard and latest on COPD, retinoic acid and research. CSPR annual seminar; Letter from Tom "Oxymorons and other Species"

A belated valentine from all of us, to all of you, especially long time reader 89 year old "asthmatic Cowboy Ed Smith". 



We were amused to receive a *yellowed* newspaper clipping about Spiriva from "Cowboy Ed". He wondered what has happened in the years, and it *has* been years, since he first read about it. If you receive Enews from PERF, you already know that in January Boehringer Ingelheim Pharmaceuticals, Inc. announced that

the United States Food and Drug Administration (FDA) approved Spiriva<sup>®</sup> HandiHaler<sup>®</sup> (tiotropium bromide inhalation powder) for the long-term, once-daily maintenance treatment of bronchospasm associated with Chronic Obstructive Pulmonary Disease (COPD) which includes chronic bronchitis and emphysema. *At last!* As many of you know, it has been available in Europe and other parts of the world for many months. No one should think that Spiriva is

anything like a cure for COPD, but it seems to be a nice addition to the bronchodilator treatments we have at present.

Spiriva<sup>®</sup>, is the first inhaled anticholinergic medication to provide significant and sustained improvements in lung function with once-daily dosing. This drug is closely related to ipratropium bromide (Atrovent), but has a much longer duration of action. Spiriva<sup>®</sup> works through targeting of the primary reversible component of COPD, constriction of the airways, and helps COPD patients breathe easier by opening narrowed airways and helping to keep them open for 24 hours. According to treatment guidelines of the Global Initiative for Chronic Obstructive Lung Disease (GOLD), long-acting bronchodilators are the preferred treatment option for COPD *maintenance* therapy.

Spiriva<sup>®</sup> provides significant improvements in key measures of lung function and represents a major advance in the treatment of all stages of COPD,” said Dennis E. Doherty, MD, chairman of the National Lung Health Education Program and Professor of Medicine and Chief of the Division of Pulmonary and Critical Care Medicine at the University of Kentucky Medical Center. “Spiriva<sup>®</sup> will become a first-line maintenance treatment for patients with mild to severe COPD. Patients may be able to control their

symptoms for a full 24 hours with scheduled once-a-day use.”

As an anticholinergic drug, Spiriva<sup>®</sup> must be used with caution in patients with glaucoma and prostatic hyperplasia, as it occasionally may worsen symptoms of these conditions.

It will be several more months before it is available in American pharmacies. Be prepared for sticker shock.

Along with the yellowed clipping Ed sent a copy of his autobiography “*The Wandering, Trapping and Trading Cowboy*” with the inscription “Where trails cross, friends meet”. The story of his life on the Dakota Rosebud Indian Reservation, in cow camps, and as a hunter, packer and guide in the far West is a slice of Americana out of the pages of Louis L’Amour. And so is rolling *Bull Durhams* as a symbol of manhood even when you are a five year old! Marlboro Man, make room for Bull Durham and our own Cowboy Ed! 🍷🍷🍷

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*PERF board member Jeanne Rife made a very generous donation towards payment of our new printer in memory of her daughter, Gale Marie, and her mother, Bertha Sanford, both of whom died very recently. Our sympathies are with you, Jeanne.*

*Another PERF Board member, Barbara Borak, also receives our*

*deepest sympathies for the loss of her father, Elmer Lewis. His many friends made generous memorial gifts to PERF in his name.*

*The family of Jerry Donatoni called to tell us that the Second Wind helped Jerry as much as any medicine. That meant a great deal to us and we thank you for taking the time to make that call during this sad occasion. Memorials in honor of Jerry Donatoni were made by Mr. & Mrs Joseph Donatoni, Rena Legge, Pat Peller, Madeline Fish, Joan Berlin, Mary & Aldo Dellape, Mr. & Mrs. John Casey, Arthur & Florence Cohen, Wallace & Clara Ford and Arthur & Doris Golden. A memorial donation was also made by Virginia Elson in memory of David Elson. Those of us in PERF join with all of you in offering condolences to the loved ones of these departed friends and family members.*

*We also send thanks for donations to Barbara Knowles, Kris Brust, RN, John Skolfield, Jr., with very special thanks to Dave Nelson and Linda Burns!* 🕊️🕊️🕊️

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**We get mail:** *Increasing Oxygen Levels Without Oxygen:*

Several people have written something like, “I have a friend with emphysema whose oxygen levels are dropping. He was told that there are new techniques using hydrogen peroxide to drink or to use IV (intravenously) to cleanse the blood.

Can he raise the oxygen level of his blood this way?”

Sorry but the answer is **no**, if you are referring to various scams out there that say you can increase blood oxygen levels with a pill or drink of some sort. Do **NOT** let your friend use herbal therapy or IV therapy to try to improve the oxygen level of the blood! Beware of people claiming to offer “quick improvement” or “cure”! These scams have been around for a long time. They offer no help, cost a lot of money, and can sometimes be *dangerous*.

Pulmonary rehab can help to improve breathing techniques, teaches pursed lip breathing, and helps to get muscles more efficient with an exercise program. An exercise program also may help to get rid of excess mucous in the lungs. These things, plus proper inhalers, help to fine tune and slightly improve oxygenation in many people.

However, the only way to *substantially* increase the oxygen level of the blood is to *breathe* it in with oxygen as prescribed by a physician. Oxygen is a medication. It can be obtained *only* with a prescription that specifies the liter flow necessary to bring the oxygen level of the blood back to a normal level. Your friend needs to talk to his physician about his concerns as soon as possible. He is fortunate to have such a caring friend as you.

**We also get letters from people who are not happy using their oxygen**

**and hope that pursed lip breathing can be used instead.**

*Dan wrote* “My COPD doctor gave me a prescription for oxygen when I am sleeping or walking around. My daily routine is going to the mall and walking for 30 to 40 minutes per day. I'm a little embarrassed to go out in public with oxygen on my body so I don't use it. I do PLB to get my oxygen up but it only lasts about 7 minutes before it goes way down again. Then I come home and gag the rest of the day. I guess I'll just wait until I can breathe better, before I use my oxygen.”

*Dear Dan:* I was so sad when I finished reading your email; sad because of how you are suffering, and sad because your rehab program didn't succeed in helping you to better understand, appreciate and take advantage of your oxygen. Of course, I don't have access to your records and only your doctor can properly advise you. He knows what your blood gasses and oxygen saturations are, and how much you need oxygen. You do need to call your physician and let him know about the problems you are having. They may be due to exercising so hard without the oxygen or they may be due to another problem. Your doctor will be able to decide that when he sees you. At that time, you also need to tell him how you feel about using oxygen so that he can help you with this. While you are waiting to hear from him, I am going

to review some general information that I hope will help you a little. I also urge you go through our past newsletters. We have written many, many articles on oxygen, why it is used, what happens when you don't, and its value in exercise. The time spent by us will be more than worthwhile if we help to convince you about the need of using your oxygen as prescribed.

I am so impressed that you make the effort to walk 30 or 40 minutes a day when you feel so miserable the rest of the day. You are one tough guy with tremendous motivation and drive. Now all we have to do is change a few attitudes and you have great potential for improving!

Lets talk about pursed lip breathing (PLB). I'm a great proponent of this and Dr. Tiep and I, with the help of enthusiastic patients, did some of the early research proving how effective it is in helping some people increase their oxygen levels. It is great for emergency use, to avoid panic, and to help bolster your oxygen levels. BUT, it is NOT a substitute for oxygen!

Exercise is one of the things that can really better your condition but NOT if it is making you so sick. So, tell me. What do you think *you* can do to make things better? I'll bet you know the answer and don't need me to say:

*Use your oxygen as prescribed by your doctor!*

Let's talk about your feelings of embarrassment. What do you think of the astronauts? I'll bet you don't think that *they* look silly using oxygen. How did you feel when you saw that "first step for mankind" on the moon? I still get chills seeing that news clip, but it wouldn't have happened if those guys tried to do it without oxygen. You may say that's different. Well, maybe, but did you know that liquid oxygen technology, and much lightweight portable equipment, is a result of our space effort? **Those astronauts were the first users of portable liquid oxygen!** Remember that, and those hero astronauts, the next time *you* feel foolish wearing oxygen. Think of yourself as also being someone out to explore new worlds and attitudes and be as proud of using this new technology as they were, and still are.

Did you know that portable oxygen has only been around for about 40 years? Also, appreciate how fortunate you are to have portable oxygen with which to walk around. Many countries in the world do not have oxygen at *all*, or have it only for the last month or so of life. And that end comes a lot sooner to those who need oxygen but don't get it *or* won't use it! Still other countries only give oxygen to those who have such low blood levels that they need it all the

time, even when vegetating in front of a TV set. There is no oxygen available for those who need it to help exercise!

You can't go back the 60's when the doctor wouldn't have been able to give you oxygen, and I guess you don't want to move to Eastern Europe or much of Indonesia and Asia where oxygen is not available. So, would you please again consider taking advantage of being an American in the 21<sup>st</sup> Century? Please! Use your oxygen to exercise!

Maybe you have the wrong portable system. Is it small and easy to carry around? If you are dragging around an antique E-cylinder, I can see why you are so resistant to using portable oxygen! E-cylinders are *not* portable. If your HMO insurance doesn't cover some of the little units, like the Helios or small lightweight compressed oxygen tanks, maybe your doctor or the staff of your rehab program can contact the HMO and help get you through the system.

If you have Medicare and a Medicare supplement, you should be able to get anything you need. With your doctor's approval and support, *insist* on a small, lightweight unit. Go down to the office of your oxygen supplier and see the various kinds they have available. If you don't already have one, ask your doctor about switching you to a more user-friendly portable

oxygen system. I know your physician will want to help. Have you heard about trans-tracheal oxygen? That is the ultimate for those who want an "invisible" portable oxygen system. Are you beginning to see how many options you have?

I haven't even started on how to use pursed lip breathing as a temporary help, or all the physiological reasons for using your oxygen as prescribed. We can review some of that at another time. But please, don't go for your next walk at the mall without your oxygen. Write back and let me know how you are doing. We care!

*[We just heard from Dan. With his doctor's help, he has been switched from a large tank too big to carry, to a Helios system. He plans to use oxygen when exercising.]*

**And a question for Dr. Casaburi:**

*When I was in my forties I took up jogging. In time, I found that I increased the length of time many times over. My question is--**did my lungs produce additional alveoli to process the increased load by my jogging or did this exercise cause the lungs to merely operate more efficiently?"***

This is really an excellent question. It is well known that regular exercise increases our ability to tolerate exercise. This is mainly a result of changes in the muscle. By a process whose mechanism is not totally

understood, exercise causes profound changes in the structure and composition of the muscle that is exercised. Muscle capillaries grow, mitochondria (the power-houses of the cell) get bigger and more numerous, and the concentration of enzymes that make the muscle work increase. The muscle is able to do a lot more work before it begins to produce lactic acid. Lactic acid is part of what makes the muscles "burn" and it also stimulates breathing. So, after training, a given amount of exercise will feel less stressful both to the muscle and to the lungs.

Some other organs adapt to exercise besides the muscles. Since it is working harder too, the heart will also have positive adaptations and, for example, heart rate will be lower at a given level of exercise. But the lung does not seem to adapt. Very clearly, the lungs do not grow alveoli in response to exercise training.

While we are waiting for the results of the FORTE study, it is worth stressing that this is not the only game in town. I know of at least one major drug company who has a drug in clinical trials aimed at stimulating alveolar growth. I suspect others will follow. I am still of the opinion that we are still quite a way from an effective way to stimulate alveolar growth. However, the more people working on this problem, the sooner we will reach this goal.

Rich Casaburi

**Steven Reynard, MD of the University of Nebraska** recently was the *Wasserman Visiting Professor for 2004* at Harbor-UCLA Medical Center. We thought you would be interested in some of the highlights of his lecture.

COPD is the 4<sup>th</sup> leading cause of death. More disturbing is the fact that there has been a 163% increase between 1965 and 1998 while every other major disease has shown a significant decline. In 2020, COPD is expected to be the 3<sup>rd</sup> leading cause of death in the US and in the world. More serious, the number of people with diagnosed COPD is thought to represent only one half to ¼ of those who actually have this condition.

There is a misperception that only 15% of those who smoke get COPD. Smokers whose lungs are damaged by smoking lose lung function at 2 times the rate of those who do *not* smoke. *Many of these people fall into the category of undiagnosed COPD.*

One of the problems of COPD is the lack of recognition by the *patient*. Many people with COPD so severe that they get short of breath with *talking* still feel that they only have a **mild** case!

Undeniable symptoms of shortness of breath with activity often do not occur

until lung function goes down to 40% of predicted. *The problem is, people will stop the activity that makes them short of breath. When you ask them if they are short of breath with activity they say, "No."* **But**, they no longer are active! With these people, improving lung function doesn't help. *You need rehab and exercise also.*

Muscle abnormalities in COPD are not just due to inactivity. There definitely are skeletal muscle abnormalities in COPD. To lose weight and muscle mass is not a good prognostic sign.

We also need to separate smoking and COPD. Smoking is an epidemic, as is COPD, but they are different from each other. About 20% of people who die of COPD have never smoked. *Even if we considered only this 20%, COPD would still be a huge health problem.* Other non-smoking causes of COPD are Alpha-1 antitrypsin defect, frequent lung infections, and some forms of asthma. Babies born with a low birth weight are also born with smaller lungs and fewer alveoli. They statistically have a larger chance of getting COPD, but NOT of getting lung cancer.

There are multiple theories about the many possible causes of COPD. While we once thought that the lung has no capacity for repair, we *now* know that is not true. 5% of lung collagen turns over every day just like

cells in the skin and bone. *Excessive* or abnormal repair leads to interstitial pulmonary fibrosis or emphysema. Possibly multiple cells are involved in repair. We *do* know that cigarette smoke alters cell response and prevents repair, as does starvation when food intake is down to 40% of what it should be. Starvation also makes emphysema worse.

The future will be to restore lung function and alleviate the suffering of our patients. Retinoic acid works in rats and grows alveoli in their lungs, but how to get it to work in *people* is the question now faced. The lung cells stimulated to grow in rats are not identical to the ones that are in people. And alveolar repair is different according to location in the lung. One technique now being researched is stem cell transplants from bone marrow cells to help make retinoic acid and other such drugs work better. There are lots of hurdles but they *are* amenable to the efforts of dedicated researchers!

The LVRS (Lung volume reduction surgery) study proved the value of pulmonary rehab. In the long run, *this* may have been more important than the value of LVRS.

*COPD is a very exciting field because of the promise of what can be done to help our patients with this debilitating disease.*

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Are you a health care professional interested in a seminar on pulmonary rehabilitation? Join us at the **California Society for Pulmonary Rehabilitation (CSPR) annual meeting April 22-23** at the Long Beach Hilton, in Long Beach, California. You will hear internationally renowned physicians like our Dr. Rich Casaburi, but also meet physicians from Norway, Russia, Japan and Hungary, who will be joining us for an exchange of ideas. For fun mixed with science, don't miss Dr. Greg Mason's talk on "Pulmonary Pachyderm Mysteries, TB or not TB". Brian Whipp, PhD, DSc will educate us on "The Ventilatory Demands of Exercise in COPD". Get 12 CEU's, or CME's, enjoy all the fine lectures we have lined up for you during the day, and socialize with this friendly group in the evening. Be sure to tell the medical director of your rehab program about this bargain! At only \$185 for members, or \$260 for non-members (*join CSPR for \$55 and save money*), it is the best educational bargain of the year. For more information, call Jim Barnett toll free at **(877) 280-2777** or check the PERF website at [www.perf2ndwind.org](http://www.perf2ndwind.org) for the brochure.

Come network with a great group devoted to pulmonary rehab. **Don't miss this meeting!** 🏠🏠🏠🏠🏠



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Dear Friends:

February 2004

## **Oxymorons and Other Species**

The dictionary says that an oxymoron is an accumulation of contradictory and incongruous terms. Examples might be "a mournful optimist" or "academic tranquility."

Now I have a different species in mind. This is a person(s) who is a moron about oxygen. This can be a patient, an oxygen supplier, and a health care provider or third party payor. But you can find oxygen morons any place you look for them.

*Oxygen morons often believe that (I have only listed 10):*

- ? Long-term oxygen therapy (LTOT) is useful only in advanced stages of respiratory diseases such as COPD. LTOT can be toxic to the lungs.
- ? Oxygen is oxygen, no matter how it is supplied. Thus tanks, concentrators and liquid portable systems are all equal.
- ? Too many patients receive LTOT. Many don't need it and it could be stopped, even in chronic stable patients.
- ? Suppliers can deliver any type of oxygen system no matter what is prescribed by the physician.
- ? Medicare will not pay for liquid portable oxygen.
- ? There is no advantage to ambulatory oxygen other than it is convenient.
- ? Enough research about how and why oxygen works has already been done.
- ? Oxygen is dangerous and may explode or start fires.
- ? Scientists actually know the mechanisms by which oxygen works in COPD and related disorders.

The facts are that lots need to be learned about oxygen and how it works. We need to encourage the development of new oxygen technologies. We need to find out why ambulatory oxygen is superior to oxygen delivered by stationary systems and why ambulatory oxygen improves survival and restores energy production in tissues. We have a long way to go to make the progress that is possible, through new research and development of LTOT.

In the meantime, remember that Medicare WILL pay for liquid portable oxygen. A supplier cannot change a doctor's prescription. Stick to your guns and fight the oxy-morons.

I'll be in touch next month.

Your friend,

Thomas L. Petty MD  
Professor of Medicine, University of Colorado Health Sciences Center  
President, Snowdrift Pulmonary Conference