



# Second Wind

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## NEWSLETTER

**SEPTEMBER**

**2001**

*PERF, The Pulmonary Education and Research Foundation, is a small but vigorous non-profit foundation. We are dedicated to providing help for those with chronic respiratory disease through education, research, and information. We hope this newsletter is worthy of our efforts.*

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Key Words: Blood donations, airline regulations flu shots, Lung Volume Reduction Surgery, FEV<sub>1</sub>, and lung function.



Many unbelievable events have occurred since we last met with each other. You have already read thousands of words, and seen hours of television, documenting the horror of the terrorist attack on our country. I will not attempt to add to the many words of those far more articulate and knowledgeable on this subject than I. But we did want you to know that PERF joins the rest of the world in expressing our shock, our sorrow, and our sympathy to those directly involved in this tragedy, to our fellow citizens of the United States, and to friends around the world. We would also like to thank our friends for the expressions of support we have received from around the globe, especially from Japan. They were appreciated.

As we watched the smoke and dust billowing and blowing across the television screen, we thought of our many readers from the New York and New Jersey area. We hope that they were spared the added burden of

having their respiratory systems impacted by the polluted air.

As calls for **blood** went out across the nation we also hoped that our readers with respiratory impairment used restraint in volunteering, or

were turned down if they did respond. Why is that? **Because oxygen is transported around your body in the hemoglobin of your red blood cells.** When your oxygen transport system is already impaired by damaged lungs, giving blood can cause you to feel short of breath and fatigued. So, no matter how patriotic you are, leave the blood donations to someone else!

Even across the nation, here in California, we felt the ripple effects of the terrorism on the East Coast. Mary Burns and Dr. Rich Casaburi were scheduled to fly to Minneapolis on the 12th for the annual AACVPR (American Association of Cardiovascular and Pulmonary Rehabilitation), meeting. Their flights were cancelled, the meeting was cancelled, and so, of course, was our planned reporting of it in this edition of the Second Wind.

A meeting in Aspen, Colorado, chaired by Dr. Petty and to be attended by Dr. Casaburi, scheduled less than a week after the tragedy on September 11<sup>th</sup> was also cancelled. This meeting was to have discussed the latest developments in pulmonary medicine.

Dr. Brian Tiep and Dr. Rich Casaburi also had their flights to Berlin, for the European Respiratory Society (ERS) annual meeting cancelled. Dr. Casaburi was able to get a flight

much later in the week and arrived in time to give his four scheduled lectures. He reports that the Europeans were also in a state of shock regarding the events in New York and were effusive in their expressions of sympathy.

And finally, the Champagne and Croquet fund raiser for PERF's Chair in Rehabilitative Sciences, planned by Barbara Borak, also became victim to the tragedy and joined the long list of cancellations.

**But what about your planned flights in the next few months, or over the Christmas and New Year holidays?** Here is the latest information from *Craig Murga* with facts you need to know before you decide to what to do.

As America searches for ways to keep the public safe and secure from terrorism, the FAA has imposed some strict guidelines on the air carrier's and airport authorities around the country. These restrictions have made travel extremely difficult, but not impossible, for those needing supplemental oxygen. As time goes on I'm sure many of the problems we are currently experiencing will be remedied, but for the time being we are all concerned that life will never be the same again. I have recently spoken with several of the

airlines, and the LAX airport authority. The information I have received is confusing at best. The FAA has reaffirmed a provision that airlines must continue to support those who need medical attention. This provision only begins when the traveler has entered the terminal. *The problem is getting to the terminal.* In the case of LAX, the airport authority is responsible for the security of the airport parking structure, buildings, and the surrounding area. The airport authority at LAX has decided to use parking lots located *outside* the main terminal as drop off points for travelers. *The only vehicles allowed inside the main terminal are taxis, limousines, parking lot shuttles, and hotel shuttles.* Only ticketed passengers are allowed within the terminal area. **This makes it impossible for oxygen providers to meet those that need oxygen support at the gates or for layovers.** As with many of the airports located in major metropolitan areas these extreme security measures may remain in place for a while, but be aware that not all airports impose the same conditions. *John Wayne Airport, just 30 minutes away, does allow private vehicles to drop off passengers at the terminal.*

The best recommendations I can offer at this time are the following.

- If driving a little farther will get take you to a direct flight, do so.
- Call the **airport security office**, NOT *airline* security, to find out what level of restrictions are being imposed at the airport. Remember, airlines are under extreme financial pressure to keep passenger use up and may unknowingly provide you with misinformation.
- If you need oxygen during a layover, most major airlines have first aid stations, or they can make arrangements through the airport clinic.
- Minimize your exertion when going from plane to plane by requesting a wheelchair and transport.
- Take advantage of the curbside wheelchair access to get you through security a little faster.
- Make prior arrangements with an oxygen provider to drop off a cylinder at your destination point with family or friends who plan to meet you as you exit the terminal.
- If you are taking carry-on luggage, minimize objects that would cause you delays, like metal nail files or aerosol cans.

- **Most of all, be patient, relax, and remember your pursed lip breathing technique!**

Thanks, Craig, for again providing us with some very helpful information. If you would like to discuss this with Craig you may call him at his Lincare office at 1-800-251-7322. We also recommend that you discuss this with your current oxygen supplier in addition to contacting any airports that you may need to use.

*Boehringer Ingelheim* made a generous donation to the Chair in lieu of an honorarium to Dr. Petty. Thanks to both BI and Dr. Petty! *Lawrence Fine* of Boynton Beach, FL joined Dr. Petty's **Long Beach 500** Club. *Peter Williams* made a donation to the Chair in memory of his son,, *Keith*. *John Boynton* of Cockeysville, MD made another of his regular generous quarterly donations.

Are you a health care professional who gets the *AARC Times*? If so, be sure to check out the *October* issue which will have an article on the last *Rally for Research*. If you are part of a hospital support group you might ask one of the respiratory therapists if they will share the article with you. It was well done.

*Ruth Brand, Freda Standeford, Donna Wilson, and Margaret Holmberg* all made donations to

PERF as did *Margaret Saul* in memory of her daughter. The PEP Pioneers made donations in memory of *Jewel Barker and Bill Purdum*. We would like to add our condolences to those who have lost loved ones.

Hot off the Press is *Inspirations: Stories of Breathing Better and Living Well*. It is written by **Jane M. Martin, RCP**, a dedicated respiratory therapist who started the pulmonary rehab program at **Holland Community Hospital, Holland MI**. this book contains personal, first person stories of patients' triumphs over respiratory disease, their thoughts and experiences as they go through this process, and even some poems they have written. It is available at

<http://www.infinitypublishing.com/>. Click on bookstore and type in the title.

There are 215 pages and photos for only \$14.95. Would you like more information? E-mail Jane directly at [jmartin@macatawa.org](mailto:jmartin@macatawa.org).

You may remember that Christopher Columbus and one of his sailors, Rodrigo de Jerez, have the dubious distinction of having brought tobacco back to Spain from America. But did you know that the first smoking ban came into effect about the same time? The next time someone complains about smoking restrictions tell them what happened to old Rodrigo. The Spanish Inquisition saw that he was

able to exhale smoke through his nose and mouth, a sure sign of *evil!* Continuing to smoke, he finally got a 3 year prison term toward the end of his life, which probably was an effective, if rather unpleasant, smoking cessation program. *Congratulations to Genny and Sal for quitting without the help of the Inquisition!*

***Flu shots.*** More on this next month, but we did want to remind you to make an appointment with your physicians NOW. The shortage won't be as bad as last year though supplies may still be late if the office didn't order early enough. Check on the status of supplies so that you can be sure of being protected during the flu season.

Results from an ongoing clinical trial conducted by *Medicare* and the *National Heart Lung and Blood Institute at the National Institutes of Health* indicate that a subgroup of patients with very severe emphysema who undergo a surgical treatment called **Lung Volume Reduction Surgery (LVRS)**, are four times more likely to die than patients receiving medical therapy only. The results are so alarming, that federal officials monitoring the clinical trial have stopped allowing certain patients with very severe emphysema to take part in the trial.

"These study results mean that

patients and providers should be cautious in evaluating the risks and benefits of LVRS in patients with severe emphysema," says ATS President Adam Wanner, MD. LVRS is a procedure whereby chest surgeons remove emphysematous lung tissue. The rationale for the procedure is that removal of emphysematous lung tissue would reduce the volume of the over-inflated lung, thereby increasing its elasticity and improving the patients' ability to breathe.

However, early results from the clinical trial have shown high mortality rates for some patients with very severe emphysema. Dr. Wanner comments, "The early data generated by the clinical trial indicates that LVRS may be a dangerous procedure for patients with severe emphysema. I appreciate the decision of the Medicare and the National Heart Lung and Blood Institute to release the study results early. The study results show just how valuable joint clinical trials sponsored by Medicare and the National Institutes of Health can be." It is worth noting that the preliminary results of this trial (and of other studies of lung volume reduction surgery) have been encouraging. It seems likely that the procedure will eventually be shown to be of some benefit to selected patients with emphysema.

Helen writes from Walnut Creek, CA “*Dr. Petty’s letter always says “Check your lungs, Know your numbers.” Is this in reference to spirometry tests and FEV<sub>1</sub> or something else?*”

Good question. Yes, Dr Petty is referring to your FEV<sub>1</sub> which is measured during your spirometry or pulmonary function tests. What is your FEV<sub>1</sub>? Literally, it is the **volume of air that you can force out of your lungs in one second after having inhaled maximally.** In other words, as much as you can.

We measure FEV<sub>1</sub> during the time you are asked to “blow out as hard as you can”. The individual without lung disease will be able to blow out 80% or more of the air in the lungs in one second. An FEV<sub>1</sub> below 80% of predicted is considered abnormal.

If you have pulmonary disease you may only be able to blow out 40% or 30% or even only 20% in one second. That would mean that your FEV<sub>1</sub> is 40% or 30% or 20% of predicted. Why do we prefer a percent rather than actual numbers? It is because a man who is 6 feet 5 inches tall will have bigger lungs, and therefore more milliliters, than a lady who may only be 5 feet tall. So, while your doctor wants to know your FEV<sub>1</sub> in milliliters, for more practical purposes the percentage may be more informative to you.

And speaking of practical, what does all this mean? The FEV<sub>1</sub> is a very important measure of your lung health and also seems to be a measure in other areas of health. *When your FEV<sub>1</sub> (as a percent of predicted) decreases it shows that your lungs are aging faster than you are.* Not so good. It may take you an *additional* three, or four or even five seconds to get all of the air out of your lungs, depending on what the decreased percentage of your lungs may be may be. This is why it is so important to concentrate on breathing **out** when you have COPD and why we tell you to do so at least 2 or 3 times as long as you breathe in. If you don’t get that old air out, there is no room for the new, oxygen rich air to get in. That is why, if you breathe in and out too rapidly, you get short of breath rather than feeling more comfortable.

Why does it take you longer to get air out of your lungs when you have COPD? It is because of a loss of elasticity causes air trapping to take place. Instead of having air rush out easily, the way it would from a full balloon, it sits there and needs to be pushed out of the lungs, the way you need to flatten a bag to get all of the air out of it.

When you go to the doctor does he or she let you know what your blood pressure is? Does your physician tell you what your cholesterol level is?

Of course! **It is just as important to have a measure of your lung function known to you.** To scare you? Of course not. Rather, to encourage you to do something about it. As an example, if your blood pressure is 160/96 would you ignore it? NO! You would probably be counseled to go on a low sodium diet and lose weight, if appropriate. You would be told to start an exercise program and then use medications, if necessary, to lower your blood pressure and prevent further problems with your health.

What do you do if your FEV<sub>1</sub> is low? It depends on the numbers, of course. Most people aren't even aware that

they have a problem until they get below 40% or 50% of predicted.

Some of the things to do at that stage would be to consider getting into a pulmonary rehab program, to start an exercise program, to use the medications (inhalers especially), recommended by your physician, and, *most* important of all, **stop smoking!** You would do all you can to protect your lungs from further damage. That includes pneumonia and flu shots. So make that appointment *today* for your flu shot and to discuss with your physician what else you can do to help your respiratory condition. .

*We received many prayers for our nation and many patriotic messages by way of our e mail, but this is a twist on Dr. Seuss rhetoric that we would like to share with you, thanks to Tisha Bullock*

Every U down in Uville liked the U.S. a lot,  
But the Binch, who lived Far East of Uville, did not.  
The Binch hated U.S! the whole U.S. way!  
Now don't ask me why, for nobody can say,  
It could be his turban was screwed on too tight.  
Or the sun from the desert had beaten too bright  
But I think the most likely reason of all  
May have been that his heart was two sizes too small.  
But, whatever the reason, his heart or his turban,  
He stood facing Uville, the part that was urban.  
"They're doing their business," he snarled from his perch.  
"They're raising their families! They're going to church!  
They're leading the world, and their empire is thriving,  
I MUST keep the S's and U's from surviving!"  
Tomorrow, he knew, all the U's and the S's,  
Would put on their pants, and their shirts, and their dresses.

They'd go to their offices, playgrounds and schools,  
And abide by their U and S values and rules.  
And then they'd do something he liked least of all,  
Every U down in U-ville, the tall and the small,  
Would stand all united, each U and each S,  
And they'd sing Uville's anthem, "God bless us! God bless!"  
All around their Twin Towers of Uville, they'd stand,  
and their voices would drown every sound in the land.  
"I must stop that singing," Binch said with a smirk,  
And he had an idea,-an idea that might work!  
The Binch stole some U airplanes in U morning hours,  
And crashed them right into the Uville Twin Towers.  
"They'll wake to disaster!" he snickered, so sour,  
"And how can they sing when they can't find a tower?"  
The Binch cocked his ear as they woke from their sleeping,  
All set to enjoy their U-wailing and weeping,  
Instead he heard something that started quite low,  
And it built up quite slow, but it started to grow.--  
And the Binch heard the most unpredictable thing....  
And he couldn't believe it--they started to sing!  
He stared down at U-ville, not trusting his eyes.  
What he saw was a shocking, disgusting surprise!  
Every U down in U-ville, the tall and the small,  
Was singing! Without any towers at all!  
He HADN'T stopped U-Ville from singing! It sung!  
For down deep in the hearts of the old and the young,  
Those Twin Towers were standing, called Hope and called Pride,  
And you can't smash the towers we hold deep inside.  
So we circle the sites where our heroes did fall,  
With a hand in each hand of the tall and the small,  
And we mourn for our losses while knowing we'll cope,  
For we still have inside that U-Pride and U-Hope.  
For America means a bit more than tall towers,  
It means more than wealth or political powers,  
It's more than our enemies ever could guess,  
**So may God Bless America! Bless Us! God Bless!**

