Second Wind
NEWSLETTER

JUNE 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.

Key words: ATS, Prevention of COPD, Early Recognition, Pulmonary Rehab, SARS, International Coalition for COPD, Meeting of National COPD Conference, Dr. Petty

ATS stands for the American Thoracic Society. Actually, as the annual meeting in May demonstrated, this is really an *international* society rather than one just for Americans. Seventeen thousand (that's right, 17,000) pulmonary physicians, scientists and other members of the pulmonary community crowded into Seattle to attend 5 days of multiple, concurrent meetings. From 7 am until 9 pm you could attend a bewildering choice of formal meetings. Additional smaller, more specialized meetings also were scheduled to take advantage of this international gathering of some of the top people in their fields. Why should you care about this? Because you need to be aware of the exciting new research, potential breakthroughs and (most importantly) the international focus now on COPD, its cause and its treatment. *COPD is now an international epidemic.* However, our attitude towards this disease, to quote Dr. Bart Celli, "*has gone from nihilism to justified optimism"*. That is, the diagnosis of COPD no longer means a hopeless condition without any known treatment or chance of improvement. We are learning

more and know that the prognosis is better than it used to be. COPD is now a preventable and treatable disease!

PREVENTION of COPD is the first step to be considered by the international community. WHO, the World Health Organization, after many years, has gotten America and Germany to join 130 countries trying to put warnings and restrictions on the sale of tobacco. While the US administration has finally signed up, this still needs the approval of a reluctant Congress! The tobacco lobby is very powerful. Some very harsh language was used at these meetings about the responsibility of the tobacco companies for worldwide health problems. **By the year 2030, it is estimated that smoking will be the earth's largest, single cause of death, with COPD itself becoming the third leading cause of death!** This will result in a worldwide catastrophe causing an estimated ten million (10,000,000) deaths a year, 70% of them in low/middle income countries. Cigarette consumption is down in the United States (with California leading the way) but the tobacco industry is getting bigger all the time! All of us should watch the votes of our representatives to see if they support the tobacco lobby. We also can join forces to stop support, and put limitations, on these companies. More on that subject later when we talk about the *National Coalition of COPD.*

EARLY RECOGNITION of COPD is now finally accepted as a necessity after years of pioneering efforts by Dr. Tom Petty and NHLEP, the organization he founded specifically for this purpose. There are 10 million to 13 million people in the United States with COPD, but many others are yet undiagnosed. It is speculated that there may be as many as 30 million in all! Why are there so many people around without proper help or diagnosis? Amazingly, many people who experience serious symptoms still regard themselves as quite normal and do not seek help. Another problem is that many family practice physicians are not familiar with spirometry. Did you know that the spirometer was invented before the blood pressure cuff? The truth of the matter is, you can't tell the extent of someone's COPD without spirometry any easier than you can tell what someone's blood pressure is without that blood pressure cuff. So, the push is on to educate medical students and interns, along with older Family Practice Physicians and Internists, in the need and interpretation of the spirometer. The earlier we can

diagnose and treat COPD, the more we can limit its impact.

Pulmonary Rehabilitation is now considered the gold standard in the care of COPD. This was stated repeatedly as being obvious by physicians from various countries, yet never ceases to send a thrill of accomplishment through those of us who have long advocated this therapy.

To give you a little history, back in 1990 after much debate the California Thoracic Society (CTS) issued a revolutionary Position Paper. Written by Drs. Richard Casaburi, Robert Chang, and Andy Ries it stated that pulmonary rehabilitation was the standard of care for the treatment of the pulmonary patient. Many pulmonary physicians at that time did not agree, but successful pulmonary rehabilitation programs in California convinced other influential physicians. They joined patients and coordinators of programs as advocates of this therapy. The position paper was not only accepted by CTS, but it triggered acceptance by other states and organizations. As additional research began to incontrovertibly prove the value of rehab, its use as a therapy spread until it is now internationally accepted. It is no longer considered a form of alternative health care.

We now know that even patients with severe disease can benefit from rehab as much as those with mild disease. To again quote Dr. Celli, "*If pulmonary rehab was a drug it would be a block buster! If a drug company was marketing it, everyone would get it!"* What a thrill to have been part of this process and to see years of belief and effort bear fruit!

Now, along with the newly recognized importance of pulmonary rehab, lets not forget that acceptance includes the use of oxygen, when necessary, and the importance of exercise. (PERF Board members Drs Rich Casaburi, Tom Petty, and Brian Tiep were all early advocates and leaders in research in these fields, but more on that another time.) The results of many clinical trials were presented reaffirming this importance, including some studies that show that the more you are able to walk, the better your life expectancy and quality of life. Your FEV_1 is no longer considered the only way to judge the impact of COPD on the individual.

Another clinical trial showed that even in a normal subject the effects of a cold, as measured by decreased muscle strength, lasted as long as a month in non-COPD patients. Now do you understand why that last bout with a virus knocked the

starch out of you? You CAN get better, so just give it time!

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The average pharmacy cost in the United States per year for each COPD patient was reported as being $1,545.00 while in other countries it is $739.00. Is that because we are getting more and better medications here or is it because drug companies are charging us more? Lots of debate on that topic. There were also many lectures on new medications including Tiotropium (better known to many of you as Spiriva). And no, we can't tell you when it will be approved by the FDA and come on the US market. "Early next year" was the word, which is the same thing said last year at ATS.

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Do you remember reading earlier remarks about COPD now being recognized as an international problem? Demonstrating this was a small meeting of the **International COPD Coalition**. Representatives of several organizations from the United States were invited to attend. Mary Burns represented PERF (as well as CSPR and CTS). 13 other countries, ranging from Australia to Russia, also were represented to discuss their common goals and problems, with Europeans estimating that 75% of those with COPD remain undiagnosed.

Restriction of smoking is becoming more common.

An amusing consequence of this, to us, is an upcoming ban on workplace smoking in the Netherlands will also include marijuana smoke. 800 Dutch "coffee shops", famous for selling cannabis, a.k.a. pot or marijuana, could see business go up in smoke. Coffee shop owners are aghast. Although cannabis is formally illegal in the Netherlands, its use and sale are tolerated under strict government conditions. Coffee shops, where customers can buy a small amount of cannabis without fear of arrest, are a major tourist draw. Smoking a joint in an Amsterdam coffee shop vies with canal boat tours and trips to the flower market for a place on many tourists' itineraries. Life is tough all over!

This session was a prelude to a larger meeting to be held this September in Vienna, Austria at the European Respiratory Society (ERS) meeting, which Mary is also planning to attend. We will keep you posted as news develops.

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We thank Dr. Selma Miller for the memorial donation to PERF in the name of Robert Myles Miller and also send our sincere sympathies to Dr. Selma Miller and the family.

Thanks once again to John Boynton for his generous donation to the Chair.

PERF also wishes to thank Jim & Posey Fraser for their PERF contribution.

Special greetings to the support group led by Craig Pottinger, Ray and Margaret Holmberg in Green Valley, AZ. We are so glad that you find our newsletter helpful! Best wishes also to Tracy Simpson RRT and her patients in Scotland County Memorial Hospital in Memphis, MO.

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The sessions on SARS attracted a large audience at ATS. There had even been pre-convention rumors that ATS would be cancelled this year due to the outbreak. We have asked PERF Board member Dr. Brian Tiep for some information to pass on to all of you. Those of you who receive the newsletter on line will (by e-mailing subscribe@secondwind.org) have already received this information as part of our policy to keep you informed on important topics.

SARS - June 2003
By Brian L Tiep, MD
Respiratory Disease Management Institute, **Pomona, CA**

SARS *stands for Severe Acute Respiratory Syndrome*. The title of this article includes a date, which emphasizes the newness of this disease and that our understanding of it is rapidly evolving. SARS was first identified in Hong Kong and Mainland China with the first cases probably occurring in November 2002. In March 2003, the **World Health Organization (WHO**) issued a warning about a flu-like illness that progresses to severe shortness of breath and pneumonia. Several people died but most recovered. SARS is highly contagious and some of its victims included medical personnel who treated these patients.

Symptoms of SARS
SARS begins with a fever greater than 100.4°F. It also includes headache, muscle aches and pains, generalized weakness and mild respiratory symptoms initially. Some people have had diarrhea. After 2 to 7 days, they may develop a dry cough and become short of breath; it may progress to pneumonia. Those with severe cases may require mechanical ventilation.

SARS Worldwide
From November 2002 to June 5 2003,**[** there have been 7,478 cases worldwide in 28 countries. 779 people have died bringing the mortality rate to 10.4%. The risk of death appears to be higher if the person has coexisting health conditions including diabetes and

COPD. In the USA 379 SARS cases have been identified in 40 states. 311 (82%) of these cases have been classified as suspected SARS and 68 (18%) (in 24 states) were confirmed. There have been no reported deaths from SARS in the USA.

Originally, the SARS virus probably came from animal reservoirs, perhaps around the Guangdong Province of China. People at greatest risk for the development of SARS in the USA have been traveling in epidemic areas of the world. These areas include: China, Hong Kong, Vietnam, Singapore, Taiwan and Toronto, Canada.

Treatment of SARS

There is not yet any specific treatment to kill the infection. SARS is believed to be caused by a corona virus, which is a first cousin to viruses that cause the common cold. No antibiotic, antiviral or protease inhibitor seems to help. Most people get better with generalized supportive care. It is important to begin treatment at the earliest stage of the disease both for the patient, and to prevent spread of the disease.

Preventing the Spread of SARS

Respiratory droplets spread the virus, just as they do for the common cold. Two strategies have been utilized to protect against the spread of infectious and contagious diseases: quarantine and isolation. Quarantine is for people who have been exposed but are not yet ill. Separating exposed individuals from the rest of the public is very effective at preventing the spread of SARS. Generally the patient remains at home with measures in place to protect other members of the family.

Isolation is for patients who already have SARS. Isolation is a stricter measure to protect healthy people including health care workers. People in isolation may be cared for in their homes, in hospitals, or at designated health care facilities. In most cases, isolation is voluntary; however, many levels of government (federal, state, and local) have the basic authority to compel isolation of sick people to protect the public. Those whose illness is mild may be cared for at home with measures to protect other family members. *Masks, gloves and good hand washing are essential*. Do not share linen or eating utensils. SARS patients are asked to remain isolated until 10 days after the resolution of the fever, provided their respiratory symptoms have also resolved. Other household members must be monitored for the development of SARS.

SARS Research

Fortunately, some of the world's best scientists have been working hard to understand the illness and develop a treatment for it. Some scientists believe that a vaccine is possible, although such a vaccine will be a challenge to develop. Both the CDC and WHO are working "feverishly" to protect against the spread of SARS.

Protecting yourself against SARS. It is best to avoid travel to infected areas of the world. You and your companions should wash your hands frequently and well. Universal precautions are recommended by the CDC for health care facilities to avoid the spread of SARS. These include hand washing, gloves, masks, gowns, and foot covering. Masks have not been recommended for public areas. If you or someone you know begins to develop SARS symptoms and you have traveled to infected areas, or have been in close contact with a person infected with SARS, seek help immediately! Do not wait! This approach will protect you and others around you.

Best Strategy

At this point, our best advice is to stay informed, live healthy with good nutrition and adequate exercise and practice effective hand washing both at home and when you are out in public. Check the CDC Website for the latest information at www.cdc.gov. Also, you may call the CDC at (888) 246-2675 (English), (888) 246-2857 (Español).

Our thanks to Dr. Tiep for this timely article. We will keep you updated as new information is released.

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The first National COPD Conference will take place on November 14-15, 2003 at the Sheraton National Hotel in Arlington, VA. This groundbreaking conference will be presented by the US COPD Coalition, of which PERF is one of 28 partners. This national group effort will bring together leaders in COPD management, education, research, patient advocacy, funding and public policy to chart a course of effective action against this disease. By having everyone work together, it is hoped that we can achieve that which we haven't been able to accomplish working alone. The program has been designed to encourage the participation of *all* individuals and organizations trying to make a difference in COPD. Participants will bring together their diverse perspectives to define a set of action items at the Conference. It is especially hoped that patients will attend and everything possible will be done to make it easier for them to do so.

Are *you* interested in attending? Early registration is $300. Check the US COPD website at www.uscopd.com for the conference program, speakers and all other information. You can also call the conference office at 1-888-876-1120 or e-mail USCOPD@congresscan.com for further registration and Conference information.

One of the hot topics at ATS was the results of NETT, The National Emphysema Treatment Trial. This trial determined the benefits of the best medical care (including pulmonary rehabilitation) plus lung volume reduction surgery as compared to the best medical care alone**.** The auditorium was filled to capacity for the 3-hour session. There is no way we can do a good job of presenting this information in the space left in this month's newsletter, but we promise to write it up in the next edition. ▼ ▼ ▼

Update on Dr. Tom Petty: we've had many calls and requests for information on the condition of Dr. Petty, so here is the good news that comes *directly* from him.

Tom's on the mend, and is now "one of us!"

Dear Friends,

I cannot tell you in words with enough meaning what your thoughts, prayers and letters of encouragement have meant to me! Just briefly, I sailed through surgery and was out of the hospital in 5 days. An unofficial indoor record for the Mayo Clinic as my surgeon put it. But on return to Denver, there was a strong suggestion of a pulmonary embolus. The test was negative, but required dye to be injected. This injured my kidneys for a couple of days. It also caused a severe lung reaction with bronchospasm to complicate my mild to moderate asthma that I have had for a long time. Now, guess what? I am on home oxygen. I sleep with it and will need it when I go to Aspen tomorrow to attend my lung conference. I will proudly attend with the assistance of oxygen. More later as the fascinating story of life, recovery, love and hope continues.

Tom

As we told you in our last edition, Dr. Petty has never missed even one month of writing a letter to The Second Wind since his first one back in 1985. He was determined not to break his record. He wrote the following letter for this month *before* his surgery!