



# Second Wind

## NEWSLETTER

July 2006

*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, nor 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.*

### PERF BOARD OF DIRECTORS

Richard Casaburi, PhD, MD, President  
Alvin Grancell, Vice President  
Mary Burns, RN, BS. Executive VP  
Jean Hughes, Treasurer  
Janos Porszasz, MD, PhD, Webmaster  
Alvin Hughes  
Barbara Jean Borak  
Brian L. Tiep, MD  
Peter D. Pettler, Esq.  
James Barnett, RRT, RCP  
Thomas L. Petty, MD, President Emeritus

S.1932, Home Oxygen Patient Protection Act of 2006 HR5133, Google search of PERF, Altitude and Oxygen, News from ATS; Breathing patterns for shortness of breath

**Have you heard about the portion of S.1932, the Senate Deficit Reduction Act of 2005, that relates to oxygen users?** This portion, inserted at the last minute by Congressman Bill Thomas, Republican of Bakersfield, CA, will impact the lives of all oxygen users now and in the future if allowed to stand unchanged. In response to this disastrous provision **Congressman Joe Schwarz**, MD, a Republican from Michigan, introduced **HR 5133** (also known as the "*Home Oxygen Patient Protection Act of 2006*") in the House of Representatives. **Congressman Tom Price**, MD, a Democrat from Georgia, co-sponsored this bill. We congratulate these

two Congressmen, and the others who have joined them, for their bipartisan efforts in a Congress not known for bipartisanship. While they represent both parties, they also both are physicians who understand the serious disruption S1932 will have on oxygen delivery systems in this country. These Congressmen need your support!

Pulmonary nurse Chris Garvey has done such an excellent job of explaining these laws to her colleagues and friends that we will copy her letter for you rather than rewriting one of our own. But first, we would like you to read the letter of support written by Dr. Tom Petty to Congressman Joe Schwarz for HR 5133.

# **.THOMAS L. PETTY, M.D.**

**Professor of Medicine  
University of Colorado Health Sciences Center  
899 Logan Street, Suite 103  
Denver, Colorado 80203-3154  
Phone: 303 996 0868  
Shared Fax: 303 831 6035  
Email: [TLPdoc@aol.com](mailto:TLPdoc@aol.com)**

---

May 30, 2006

Via E-Mail and FAX

Honorable Joe Schwarz  
United States Congress  
7<sup>th</sup> District of Michigan  
House of Representatives  
128 Cannon House Office Building  
Washington, DC 20515

Dear Representative Schwarz:

I wish to applaud the leadership of you and your co-sponsors of HR 5513, which will help the future of patients requiring long term home oxygen (LTOT). I hope your proposal will result in a revamping of oxygen reimbursement, and recognize the advantages of ambulatory oxygen, which has a strong scientific foundation.

LTOT began in Denver at the University of Colorado with our work in 1965, first published in 1967. We demonstrated a dramatic reduction in the strain on the heart and a great improvement in exercise and quality of life with ambulatory oxygen. Later I chaired the Nocturnal Oxygen Therapy Trial (NOTT), which was one of two major international studies that showed that LTOT improved survival. This landmark study was funded by the National Heart, Lung and Blood Institute. Ambulatory oxygen resulted in better survival than stationary

oxygen. Hospitalizations were far less frequent in ambulatory vs stationary oxygen patients.

We now have the technology to make "wearable oxygen" which weighs about 4.5 lb, which is another giant step in improving the quality of life in LTOT patients. Reimbursement for ambulatory patients must be greater than for home bound patients for obvious reasons of cost to the supplier. At today's reimbursement rate of about \$2400 per year, and one day of hospitalization for COPD costing \$3600 per day, the decision seems obvious. I recognize the difference between Medicare A and reimbursement budgets, but it is still money in the national budget!

As one of the pioneers who helped begin the movement to LTOT, which now serves 1.2 million Americans, I hope your efforts in gaining passage of your important legislation are successful. For the past 20 years, I have organized and co-chaired six Oxygen Consensus Conferences. The most recent was published this month.

If I can be of any assistance to you or your aides, I would be delighted to help.

Sincerely yours,



Thomas L. Petty, M.D.  
Professor of Medicine  
University of Colorado Health Science Center  
President, Snowdrift Pulmonary Conference

◆◆◆◆◆

**And here is the letter from Chris explaining what these laws mean.**

I am normally reluctant to request political involvement of others. However, recent legislation has the potential to leave home oxygen users with sole responsibility for maintenance and replacement of their home oxygen equipment. The Deficit Reduction Act passed by Congress earlier this year will require persons using oxygen to assume ownership and responsibility for their home oxygen equipment after 36 months of rental under Medicare. This potentially leaves frail persons with the responsibility to repair, replace, maintain and troubleshoot equipment that may keep them clinically stable at home.

I am asking you to consider supporting the Home Oxygen Patient Protection Act. This bill would change Medicare oxygen coverage back to its previous state, which provides allowance for ongoing maintenance and support from respiratory therapists and medical equipment companies.

This legislation was introduced in the House of Representatives by two physicians; Congressman Joe Schwarz MD of Michigan and Congressman Tom Price MD of Georgia. It is clear that Medicare spending must be controlled, however, making oxygen-dependent patients serve as their own respiratory therapists and medical equipment

company can only result in increased ER visits and overall Medicare costs.

Please consider asking your Member of Congress to cosponsor H.R. 5513, the Home Oxygen Patient Protection Act. **The switchboard number at the U.S. Capitol is 202-224-3121.** You can look up your Member of Congress and at [www.house.gov](http://www.house.gov)

Chris Garvey FNP, MSN, MPA  
◆◆◆

Thanks to both Dr. Petty and Chris Garvey for informing us about these laws. We hope that all of you get involved and call and/or email your regional member of Congress to express your views. We leave you with one last thought from Dr. Petty, himself a user of oxygen.

*“It will be key for ambulatory patients to speak loudly about quality of life, productivity, and prevention of hospitalizations to Congress. Good luck. Tom”*

◆◆◆

**Progress around the world!**

**The government of Korea** started funding oxygen concentrators in June of this year. They are also interested in starting pulmonary rehabilitation programs.

**The Japanese government** in April of this year started to **reimburse smoking cessation programs** in an all out effort to curtail the smoking rate in their country. By doing so, they hope to help

prevent a variety of cancers, COPD and the other diseases that we know are caused by cigarette smoke. The world health community now acknowledges that cigarette smoke is the number one preventable cause of death and disease in the world.

Smoking cessation reimbursement isn't the only enlightened ruling made by the Japanese Ministry of Health this year. As of June they will also **reimburse for pulmonary rehabilitation**. Way to go, Japan! To paraphrase those old cigarette commercials, "You've come a long way in the past 10 years!". We congratulate our Japanese friends for having successfully convinced the Government of the long-term benefits of these reimbursements and hope many other countries, like the United States for one, will soon emulate you.



*We would like to thank Phil Whiting for his donation to PERF. Very special thanks from Mary, as well as from PERF, for the donation from Dr. & Mrs. David and Robin Lewis in honor of Mary Burns.*

*The PEP Pioneers made donations to PERF in memory of Olesley Cole, Marian Nemec, Zina Stagnaro, Kay Arndt, Pat Blay, Marjorie Baxter, Moe O'Leary, Clare Kennedy, Joe Litzinger, Bonnie McCarthy, Barbara White, Bill Gaugh, Hubert Swisher, Michael Scholnick, and Betty Sanford. Dale & Robin Christie sent a donation in memory of Katie Beckley, as did*

*Gianina Donatoni in memory of Jerry Donatoni.*

Our thanks to all of you who thought of PERF when remembering those special to you. We join you in honoring them.



### **Have you ever Googled our PERF web site?**

If you are unaware of the power of the Internet, and the Google search engine, we'd like to share a story with you. Some weeks ago we received an email from Holland. Unlike most of our emails, this wasn't a question about pulmonary disease. It was a search for two long lost friends. A Google search of the Internet had resulted in only one hit; our PERF website. PERF had acknowledged memorial donations made by these missing friends two and one half years ago. We have a firm policy of never giving out any addresses at any time. But a series of emails exchanged with Holland gradually convinced us this was a special case. We decided to do our best to help without violating privacy standards.

The two "girls" our Dutch email correspondent was looking for had been Chinese refugees fleeing from Indonesia. They had lived with her mother-in-law's family in Holland for several years---- *about 50 years ago!* Her family remembered them fondly, and wanted these lost friends to know her mother-in-law had recently died.

This is a long story about many phone calls, and several weeks of frustrating failure before we finally located the family for whom the memorial had been dedicated. They were as amazed as we by the series of circumstances leading to our call and also promised to do their best to reconnect these two families. More time passed. *Finally* our lost donors were found and they were *very* happy to again be able to share memories and greetings with their long lost friends in Holland!

Weeks later there is still a sense of awe as we ponder on how these two families, separated by years and by distance, connected again thanks to Google, and thanks to a memorial donation to PERF.



**The recommendations of the 6<sup>th</sup> Long-Term Oxygen Therapy Consensus Conference** were published in *Respiratory Care* May 2006 Vol. 51 No 5. Your pulmonary rehab team may be interested in reading it.

The recent **American Thoracic Society (ATS) position paper on pulmonary rehabilitation** can now be read in English or Spanish on the ATS website, [www.thoracic.org](http://www.thoracic.org).

**Essentials of Pulmonary Rehabilitation** by Dr. Tom Petty, Dr. Brian Tjep and Mary Burns can now also be found on the ATS website. It first hit the Internet on our own PERF website [www.perf2ndwind.org](http://www.perf2ndwind.org) and has

been widely copied since then. We are *very* pleased and honored!



### More email questions of general interest

**Altitude and oxygen** I Live in Colorado Springs, more than 5'200 ft above sea level. I am on oxygen 24/7 at 2 liters per minute (lpm). If I spend 3 months near the coast in Southern California is it possible I might not need to wear oxygen this summer?

Sure it's possible. But only your pulmonologist will be able to tell you for sure. First get the highest altitude at which you will be staying in California. Even the foothills are minor compared with anything near Colorado Springs, but your doctor will want that information. He may be able to give you a yes or no answer right away, depending on your condition and your blood gases, or he may want to do a HAST study. This is a simple High Altitude Simulation Test to see what your oxygen level is at a certain altitude. Usually it is done for patients going UP to the mountains but there is no reason why you wouldn't have one for the opposite reason. Medicare and private insurance should pay for it, but ask in advance.

If you get the okay for being without oxygen where you will be staying this summer, be sure you consider altitudes

you encounter coming and going while in transit or during your visit. If the doctor decides that you just need oxygen while sleeping; it should be easy for you to arrange to have a concentrator delivered to where you are staying before you get there. If you have a national company your regular insurance should smoothly take care of expenses but ask! You don't want any surprises. Have a great vacation!



Did you know that 100 years ago the average age for American men was only 46 while for women it was only 48?



### **New information from ATS**

**Smoking** is the stimulant that starts an inflammatory process in *everyone* who smokes. There is an almost 3 fold increase in the white blood cells in the lung tissues. This process is still not understood. It is suspected that there is some sort of cellular defense in those that do *not* develop COPD with smoking. However it is also believed that this inflammatory process causes many diseases other than COPD such as cancer of the lung, atherosclerosis and cardiovascular disease, among others. As you have read before, COPD is not just a disease of the lungs but also a systemic disease. A lowered FEV<sub>1</sub> (the amount of air you can force out of your lungs in one second) is a strong

predictor for all sources of mortality, not just a sign of pulmonary disease. In fact it is probably a better predictor of cardiovascular disease than of pulmonary disease. Co-morbidities are increased when COPD is present. That means there may be other systems besides the lungs damaged when we have COPD.

**COPD is a *syndrome* rather than a single disease.** When a patient has COPD, the *whole* patient should be treated and examined to make sure there are no other problems present. Physicians should have a patient-centered approach and treat the whole patient, not just the disease of COPD.

While the FEV<sub>1</sub> is still a disease marker used to evaluate the severity of COPD, **exercise capacity and distance walked in the 6-minute walk are probably more significant markers.** Why is that good news? *Because you CAN improve your exercise capacity!* Physical activity is a *behavior* and behaviors can be learned. Do you have exertional dyspnea? Dyspnea can be controlled with pacing and breathing techniques. Remember that physical exertion is one of the keys to improving yourself!

**An acute exacerbation in COPD is the equivalent of the MI (myocardial infarction) in cardiac disease.** It is to be taken very seriously and prevented with all means possible. Everyone should learn the early warning signs of exacerbation such as increased fatigue,

increased sputum and increased cough. We usually think exacerbations are infections, but 52% are non-bacterial and not responsive to antibiotics. Besides viral infections it is now thought other causes may be possible, such as an autoimmune component among others.

**If hospitalization is required**, it is *essential* that activity be started again as soon as possible. Some resistance exercises, at the very least, should be started while still in the hospital. Muscular atrophy is very serious and needs to be prevented as much as possible.

*It is a myth that there is no effective treatment for COPD other than smoking cessation.*

**Pulmonary rehabilitation is being seen as the treatment of choice**, in that it helps to prevent exacerbations and increase exercise tolerance. Dr. Barry Make also added that he never uses anti-depressants for his COPD patients. He said (and we agree) that pulmonary rehab is the most effective treatment for depression and far more effective than any medication.

And don't forget that other great new study we reported last month. It is worth repeating. We all know that **pacing and breathing techniques learned in pulmonary rehab help to**

**control shortness of breath and make exercising easier.** Pursed lip breathing combined with *slow* respirations, and breathing *out* longer than breathing in are what you should aim for.

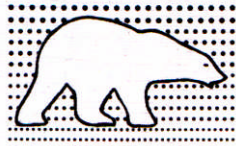
**By slow we mean 16 breaths or less a minute.** (Many patients average 12) **Research now shows that even 20 breaths a minute can cause a marked increase in air trapping, which causes increased shortness of breath and feelings of suffocation.**

We now have proof for what we have been telling you in rehab for many years. This is one time when you can't trust your instincts. When you feel most short of breath is when it is most important for you to *slow* your respiratory rate! Nice slow breaths, concentrating on breathing *out* two or three times longer than you breathe in, can relieve that sense of shortness of breath and prevent panic attacks. Many of you already know this. But if you don't, please give this a try. Pass the word on to all of your friends and let us know it this information has been of help. We really care.

Have a nice summer and stay well! ☺☺☺



**Snowdrift  
Pulmonary  
Conference**



**The Snowdrift  
Pulmonary  
Conference**

899 Logan Street, Suite 203  
Denver, CO 80203-3154  
Phone: 303 996-0868  
Shared FAX: 303 996-  
0870  
E-mail: [tlpdoc@aol.com](mailto:tlpdoc@aol.com)

**Senior Moderator**

**Thomas L. Petty, M.D.**  
Professor of Medicine  
University of Colorado  
School of Medicine  
Denver, Colorado

---

July 2006

Second Wind  
Lomita, California

### Orange Highway Cones

Dear Friends.

Every driver encounters these "signs of progress". Often these cones are lined up for miles with no evidence of any highway work being done. Or they may be blown down by the wind or traffic and present a driving hazard.

Occasionally they are in an area where about a dozen men are clustered around a few trucks and some highway repair equipment. In most cases only two or three men are really working. The others must be supervising. So it is with government (state or federal) project. Our tax dollars at work?!

But why so many, and often without an obvious purpose? I have concluded that there is no place to store them, when highway projects are completed or not yet started. Another possibility I have considered is that they somehow clone themselves. I know little about orange highway cone reproduction, but can believe that it is a prolific process.

What should we do about these ubiquitous cones? I have considered writing a poem about them. "Ode to a highway cone". There are many possible rhymes: bone, drone, moan, stone, etc.

I'll be in touch next issue.

Your friend,

Thomas L. Petty, M.D.

*Professor of Medicine, UCHSC  
President, Snowdrift Pulmonary Conference*



**Pulmonary Education and Research Foundation**  
P.O. Box 1133, Lomita, California 90717-5133

**CONTRIBUTING EDITORS**

Mary Burns, RN, BS  
Richard Casaburi, Ph.D., MD  
Thomas L. Petty, MD

July 2006



To subscribe to the Second Wind send \$20.00 to PERF, P.O. Box 1133, Lomita, CA 90717. Subscriptions are also available for those who cannot afford an annual payment of \$20.00. The expiration date of your newsletter is on your label. The newsletter is also on our Website at [www.perf2ndwind.org](http://www.perf2ndwind.org).