



# Second Wind

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## NEWSLETTER

NOVEMBER-DECEMBER 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.*

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National COPD Conference, COPD Caucus, PERF Award, Test your lungs, Know your numbers, Merry Christmas and a Healthy Happy New Year!

Merry Christmas, Happy Holidays and a very Happy New Year to all!

The first National COPD Conference was *exciting!* Held November 14-15 in Arlington, Virginia, it was attended by more



than 500 patients, health care professionals, and well-known physicians. Also, there were representatives of organizat-

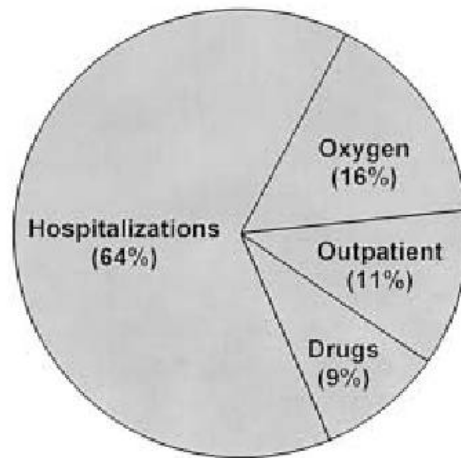
ions such as ALA (American Lung Association), ATS (American Thoracic Society), ACCP (American College of Chest Physicians), AACVPR (American Association of Cardiovascular and Pulmonary Rehabilitation) and, very importantly, representatives from the government. Mary Burns represented PERF, the Pulmonary Education & Research Foundation. There were many others, too many to name, who were there representing other patient groups.

How wonderful to renew old acquaintances or finally meet these folks we knew only through email communications! If only you could feel the surge of warmth, excitement and energy in those rooms when all these terrific people came together.

**Rear Admiral Christina Beato, MD, Acting Assistant Secretary of Health and Human Services** is the principal advisor on health policy and medical and scientific matters to Secretary Tommy Thompson. She said that Health and Human Services will focus more on *disease prevention* in the future. Medicare reimbursement for preventative and early diagnosis screenings with spirometry are going to be looked at and probably considered as a standard of care, as mammograms and flu shots already are. What does this mean? It sounds like the Feds will start reimbursing diagnostic screening with spirometry in the near future. About one half of those afflicted don't even know that they have a problem; COPD usually is not diagnosed until half of lung function is lost. Can you believe that in addition to the 14 million *diagnosed* with COPD there are probably more than 10 to 16 million *undiagnosed*? With better screening techniques it is hoped that these unidentified individuals can be found and helped. (Did you

know that abnormal spirometry is a marker for many diseases besides COPD?) Early detection of COPD with spirometry is something that Dr. Tom Petty has been fighting to achieve for many years. What wonderful news for him, and for all of us.

More active management of COPD using evidence-based guidelines is also going to be emphasized. The majority of patients see a primary care physician. These doctors often miss the signs of COPD until it reaches an advanced stage. By using guidelines, it is hoped that more patients will receive treatment at an earlier stage. It was suggested that these guidelines be given to patients, as are those for asthma.



Did you know that COPD costs 30 billion dollars a year in medical costs? As the pie chart above shows, a large fraction of the direct costs of COPD are spent on

hospitalizations for exacerbations. The number of exacerbations a patient has is, of course, associated with mortality. Three months after getting sick many patients have not yet returned to their baseline. And yet, only 50% of patients get their annual flu shot. Preventing exacerbations is important to survival!

All speakers at the meeting stressed the importance of spirometry for early identification, and the need for smoking cessation. Smoking causes 90% of COPD. The other causes include alpha-1 antitrypsin deficiency, and (perhaps) low birth weight and frequent childhood infections. Scientists, however, are beginning to find genetic links in addition to alpha-1 antitrypsin deficiency. Do you know a family in which many of the family members are smokers and all of the smokers have COPD...and other families where none of the smokers have COPD? This suggests that there are genetic links for COPD. There are apparently chromosomal



abnormalities that will cause you to get COPD if you smoke. It is a difficult disease to study and

research because low level lung destruction takes time.

Do you know how your tax dollars are spent for research? Research expenditures per death are as follows:

|                |              |
|----------------|--------------|
| HIV            | \$42,206     |
| Kidney disease | \$13,414     |
| Liver disease  | \$6,756      |
| All Cancers    | \$4,723      |
| <b>COPD</b>    | <b>\$508</b> |

However, a scientific revolution is here and there is great promise! The more we learn about what causes COPD, the more our opportunities to find cures.

Oxygen, and competitive bidding for oxygen, was discussed only in Round Table breakout sessions. Perhaps this is because oxygen has long been recognized as a proven therapy for extending life for those who need it. Cinda Claprod, of Citrus Valley Hospital in Covina, and Mary Burns, flew in to the Conference a day early in order to visit the office of Congresswoman Jane Harman (D-CA) and discuss competitive bidding for oxygen. A bill facilitating competitive bidding for home health care equipment is working its way through Congress and our fear is that it will restrict access to ambulatory oxygen. Brian Adkins, the lawyer in Jane Harman's office who met with Cinda and Mary, was receptive, asked a lot of intelligent questions,

and has since written back to tell us that he inserted a section on competitive bidding in his recommendations on the bill for the Congresswoman and spoke with her on this at length. We were pleased.

Those of us in the clinical trenches were disappointed that most speakers made only a brief mention of the importance of pulmonary rehabilitation. An exception to this was John Walsh, who stressed the value of rehab during one of most inspiring lectures of the conference. John is President and CEO of the Alpha-1 Foundation and regularly testifies to Congress and advisory groups as a patient. He was diagnosed with alpha-1 antitrypsin deficiency in 1989. Individual physicians, and all of the patients who came to the mike, also stressed the importance of rehab and the immense difference it had made in helping to improve lives.

**Did you know that...**

**Only 14% of the population knows what “COPD” means, and that includes many people diagnosed with it!** There was talk about changing the term COPD to something that sounds “nicer”, but Dr. Bart Celli shot this down saying, “If you can make SARS a household word in a few months you can make COPD known also!” Most attendees seemed to agree, so

now all of us need to join the big push for recognition of COPD. A major goal of the conference, and for all of us, is to make the term **COPD** a *household* word. But, we need lots of help to do so, YOUR help!

**Senator Mike Crapo (R-ID)** is the younger brother of the two well-known Drs. Crapo, both of whom are pulmonary medicine doctors. In September, he introduced the Senate resolution that established November 2003 as National COPD Awareness Month. When speaking to our group he admitted that he had become aware of the term COPD only a few months before that. This common lack of knowledge, he declared, is truly amazing! **COPD is the 4<sup>th</sup> leading cause of death in the United States, and in the World, and is the only one of the 10 leading causes of death for which death rate is increasing. COPD is expected to be the 3<sup>rd</sup> cause of death within 20 years.** WHO (World Health Organization) considers COPD a top *international* priority. Shouldn't it be a priority for the United States also?

Then came one of the most exciting accomplishments of this conference. Senator Crapo declared that he will propose a **COPD Caucus aimed at helping the legislature, and the country,**

**to also become aware of this problem and to start attacking and treating it.** Without this knowledge, there will be no legislative push for the funding of research, portable oxygen or pulmonary rehabilitation. He went into a great deal of detail about what could be done to accomplish this. He warned us all, however, that **this Caucus would be of no value unless many other Senators and Representatives joined him.** He urged all of us to contact the Senators and Representatives from each of our home states to join in making this COPD Caucus a force for change.

Never let your elected representatives forget that **there are 14 million people diagnosed with COPD in the US and an estimated 10 to 14 million still undiagnosed. That's a lot of potential voters, especially when you add in all the concerned family members! We need to make our problem known and we have the potential clout to do it!** Political differences were forgotten as we all joined in supporting our common cause. Senator Crapo received a long, standing ovation, which doesn't happen very often at this sort of meeting.

Mary has already sent e-mail letters regarding the proposed COPD Caucus to her legislators. We urge

all of our readers to do the same! E-mail or send a letter to your Senators and Congressmen. Make them aware of the term **COPD** and urge them to join the **COPD Caucus!** It was recommended that our letters not be too long, but it is hard to be informative and brief at the same time! If you get a successful response to your efforts, let us know. We will print an honor roll of those who join this effort in future Second Wind issues.

Ask your friends, neighbors, and acquaintances if they know what **COPD** stands for. Educate them! We need all of *you* to join in this campaign to make COPD a household word, and to convince our national representatives to join this COPD Caucus. Bring your patient clubs on board in this effort. Just e-mailing your representatives **"Make COPD a household word. Join the COPD Caucus!"** would be of great help if we all participate. Only by getting Washington involved will we get the funding and the legislation we need to help us win this battle.

Whew! This has been a tough issue to write. Deciphering pages of notes and memories, from days of talks, and condensing them into a few pages was difficult. It was also a big responsibility. We wanted to convey to you the excitement that we felt on leaving this conference.

We wanted to energize you enough to help us achieve the goals we are all striving for. We wanted to have you enter the New Year filled with positive anticipation of the future. I hope we succeeded.

*Members of the PERF Board of Directors strongly believe in their mission and are among its most generous donors. For their time, commitment and financial assistance we thank Drs. Rich Casaburi, Tom Petty and Brian Tiep in addition to Alvin Grancell, Jeanne Rife, Alvin & Jean Hughes, Pete Pettler, Barbara Borak and Mary Burns.*

*Thanks also to Mickee Heumann, Gladys Mollison, Edgar Whittemore, Barbara Butler, Elizabeth Krantz, Edith Winning, Leonard Boughton, Gloria Murray, Janice Kennedy, Priscilla Mills, Dwain Essig, Ann Little, Don Murphy, Alan Morrison, John Leaman of Resp. News & Views, and Margaret Chaika for their generous donations.*

*Thanks also for the donations of Sara Casaburi in honor of her son Rich, Margaret Schwarz in honor of John Schwarz, Lillian Marineau, RPT of Goffstown, NH “in memory of our pulmonary patients”, Jeanne Rife in memory of Al Parque, Billie Gaynor and Dorothy Hall in memory of Bertha Stanford, Pat*

*Blay in memory of Susana Szekely, Joe Weger in memory of Thomas J Weger, Thomas Burrows in memory of Doris, Phyllis Rincer in memory of Henry Smith, Barbara White in memory of Harry Holcomb, Chuck Gaynor and George Richey, Robert Hamblin in memory of Jeanette Hamblin, Bert and Pat Ternstrom in memory of their daughter, Staci. Memorial donations for Ginny Von Goerlitz were made by her husband Ted, her daughter, Heidi Thompson, Dolores Cellier and Phillip Schiff, who also had a matching fund donation.*

Genny Schaniel made a donation to PERF in honor of all the firefighters, and we know why. Genny’s home was a lonely survivor of the recent firestorm on Crest in El Cajon, CA. Even though she wore a mask, the smoke, dust and odor were hard for her to handle when she finally drove through the empty moonscape to her house. She can’t imagine how all those heroic firefighters endured, persevered and struggled valiantly for so many long hours in that thick, smoky air. We know many of them were left with a cough, but hope that all these healthy young non-smokers are now back to normal. We will never forget their courage.

**Therese Poitevin, CPA of the firm of Richard H. O'Hara & Co. of Placentia, California** for many years has been the CPA overseeing bookkeeping records and tax returns for PERF. She has again waived all fees for the year. It is good people like Terry that keep our expenditures low allowing all of your generous donations to be put to work rather than spent on overhead. For a small foundation such as ours, this is a very large donation, and *much* appreciated. Thank you!

Would you like to see a picture of the award that PERF received from



**Dr. Janos Porszasz, Mary Burns and Dr. Brian Tiep**

the Governors Board of the American College of Chest Physicians? The monetary award that came with this nice trophy will be used to purchase a high quality printer, allowing us to do all our printing “in house”. No more trips to the printer!



**Dr. Brian Tiep, Dr. Richard Casaburi and Mary Burns**

Are you a health care professional in pulmonary rehabilitation? If so, you may be interested in a hard copy of “Pulmonary Rehabilitation: the Critical Outcomes” from the Journal of Rehabilitation Research & Development, 40(5), Supplement 2, September/October 2003. It is available free-of-charge. E-mail [yuhasz@vard.org](mailto:yuhasz@vard.org) with your mailing address by December 15, 2003. Full text articles are also available on-line at [www.vard.org](http://www.vard.org). The purpose of the single-topic issue is to highlight three outcomes of a comprehensive pulmonary rehabilitation program: smoking cessation, symptom relief, and improved functional performance. Contributions are from national and international experts in the field. *Virginia asks* what is the meaning of “**Test Your Lungs-Know Your Numbers**” which she sees printed on Dr. Petty’s letters. What a good question to ask at this time,

Virginia. This phrase is the theme of **NLHEP (National Lung Health Education Program)** established by Dr. Petty to promote spirometry. Spirometers measure the airflow and volume of your breathing, which are indicators of lung health. These **noninvasive tests** can be done in the physician's office. The spirometer measures two important numbers; **FEV1** (the forced expiratory volume of air you exhale in one second) and forced vital capacity (**FVC**). **FEV6** (Forced Expiratory Volume in 6 seconds) is now used more often than the FVC since it is easier on the patient and equally informative for testing purposes. These numbers are simple expressions of complex processes, just like blood pressure and blood cholesterol levels measure complex processes. The numbers obtained for **FEV1** (air flow) and **FEV6 (or FVC)** (air volume) by a spirometer are important for the patient and the physician to help diagnose asthma and COPD, to monitor the course of these diseases, and their response to treatment. ***It is not possible to diagnose COPD without a pulmonary function test or spirometry.*** Everyone should know the numbers of their **FEV<sub>1</sub>** and their **FEV<sub>1</sub>/FVC ratio**, just as they know what their cholesterol levels are. For the record, minimal **normal** is an FEV<sub>1</sub> of 80% of the predicted level with an **FEV<sub>1</sub>/FVC of about**

**80%. Everyone over the age of 45, with a history of smoking, symptoms of shortness of breath, or chronic cough with sputum, should have a spirometry done.** While 14 million people in the United States have been diagnosed with COPD, remember that it is estimated that another 10 to 12 million remain undiagnosed! Don't be one of them! With spirometry, we can identify COPD and start earlier treatment. Thanks for a timely question, Virginia.

*All of us at PERF wish all of you the happiest of holiday seasons. We thank you for your generous support, and the donations we are still receiving. We know times are hard, especially for those with big medical bills. If you are unable to contribute, please know that your kind notes are as important to us as financial help. Knowing that we help you helps us to continue volunteering in the cause of COPD. It is wonderful to end the year 2003 on a positive note. It is even better to look forward to what we hope to achieve in 2004. Keep reading the Second Wind to stay informed, and have a very happy and healthy New Year.*

