

Second Wind

FEBRUARY 2002

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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Did you enjoy some guilt free chocolate on Valentine's Day? You did if you read the January "Letter from Tom". This issue of the Second Wind is also special because, in addition to his monthly letter, Dr. Petty is starting off 2002 by telling us what is new in COPD and what we can look to in the near future.

THE NEW FACE OF COPD

*by: Thomas L. Petty, MD,
Chairman, National Lung Health
Education Program*

Today the growing problem of COPD is taking on a new face. Commonly

considered a disease of older smoking males, new information is changing our perspective. COPD is better understood today and we have new targets for treatment. We recognize that the causes of COPD are multifactorial, and are related to both genetic or heritable factors and environmental pollutants. No single gene is thought to cause COPD except in the rare alpha-one antitrypsin deficiency state that is responsible for only about 3% of COPD, mostly of the emphysema type. Many other gene defects are thought to conspire to make affected families susceptible to harmful environmental pollutants. By far, the most common inciting agent is tobacco

smoke. But approximately 15% of COPD patients have COPD without active or passive smoking. And only about 15-20% of smokers ever develop COPD. So protective factors must be present in the majority of smokers. Extensive research is presently ongoing to identify these factors.

COPD is now known to progress over at least a thirty-year period. It has no symptoms in early stages. The physical examination, the chest x-ray and the electrocardiogram are not capable of diagnosing early stages of COPD. Only the spirometer, which measures airflow and air volume from fully inflated lungs, can detect early abnormalities. **When the flow value, known as the forced expiratory volume in one-second (FEV_1), falls below the normal 70% of the volume exhaled, which is the forced vital capacity (FVC), COPD is beginning.** This is because the FVC actually *rises* in early disease *before* the FEV_1 begins to fall. Thus two simple numbers, and the ratio between the two, are all that are needed in the early diagnosis of COPD.

A national health care initiative was begun in 1997 called the **National Lung Health Education Program, NLHEP**. Today the NLHEP enjoys the sponsorship of many medical associations and societies along with governmental support. The NLHEP is entirely funded by unrestricted grants from the pharmaceutical industry.

The NLHEP aims to involve all primary care physicians in the early diagnosis and treatment of COPD and related disorders. Since smokers with COPD have an extremely high risk of lung cancer, heart attack and stroke, the NLHEP is really a broad based health care initiative. **The NLHEP recommends spirometric testing in all smokers age 45 or older and anyone at any age with shortness of breath on exertion, chronic cough, excess mucus or wheeze. *Test Your Lungs, Know Your Numbers* is the battle cry of the NLHEP.**

COPD is our nation's most rapidly growing health problem. It is now the fourth most common cause of death, ahead of diabetes. It is the only cause of death in the top ten that continues to rise. In 1997 107,000 patients died of COPD. In 2002 deaths will probably reach 155,000. The death rate in women is rising much faster than in men. Soon more women than men will die of COPD, often at a younger age than men. Women are more susceptible to developing COPD from smoking than are men.

In the United States, COPD annually costs an estimated 30.1 billion dollars in both indirect and indirect costs.

It is estimated that we have 16 million people with COPD now in the USA. The NLHEP estimates that the true number is twice as large. Although we are told that 14 million people have the

chronic bronchitis type of COPD and only 2 million have emphysema, I believe these estimates are incorrect. In studies that I did years ago on whole fresh human lungs obtained at autopsy, virtually every specimen had at least some degree of emphysema. I believe that the emphysema damage is the main cause of shortness of breath and disability in COPD.

Although experimental surgery is under study today that hopes to improve some degree of lung function, this approach to treatment, even if proven better than pulmonary rehabilitation, is not the answer. The prevention of emphysema/COPD is the answer. Right now the pharmaceutical industry is developing new families of drugs to treat and prevent COPD. The possibility of drugs to heal or repair emphysema is under study. New approaches to stemming inflammation of the airways and destructive damage of alveoli are under study. But a disease can't be treated until it is diagnosed. Here is where the NLHEP comes in.

The NLHEP is in partnership with the American Association for Respiratory Care, the professional organization of the 130,000 respiratory care professionals. AARC members are in virtually all hospitals in the USA. Thus these respiratory therapists are the foot soldiers who will help implement the NLHEP.

A national organization to promote awareness, understanding and activism for better COPD diagnosis and treatment is being planned. To be named the **National Emphysema/COPD Association, NECA**, this new organization should rapidly grow and create a powerful advocacy group to help reduce the socioeconomic impact of COPD. It is hoped that all existing patient care organizations and a wide variety of other organizations will join in a ground swell to help launch the NECA this year, hopefully by October, which is planned to be the next nationwide COPD Awareness Month, proclaimed by President Bush. These constituents will be able to continue their local programs and functions, of course. The value of joining the new national organization can be considered **three Cs: communications, connections and clout.**

Still another initiative, launched this year in COPD is known as the **Global Initiative for Lung Disease, GOLD.** The GOLD has International representation, as does the NLHEP. Both the NLHEP and the GOLD are complementary. Both have similar objectives. Thus, working together, the NLHEP and GOLD should be synergistic.

Lots has happened in the forty years that I have been involved in COPD research, teaching and patient care. We did our first oxygen pilot studies in

1965 and launched our first demonstration pulmonary rehabilitation program in 1967. Since then, there has been a huge wave of interest in treating patients with the disabling symptoms that we all know are so sad and limiting in the millions of COPD patients that suffer advanced stages of disease. Today it is critical that we recognize the new face of COPD and develop programs to stem the tide of disease, even before symptoms start. We are entering a new and exciting era.

Jane Martin, RRT of Holland MI writes that the Second Wind helps to remind her that she is not the only one out there fighting the battle against lung disease. She thinks it is exciting to read about the Chair in the Rehabilitative Sciences and all the research going on, so we're sure she will be interested in this issue. Our warmest wishes to you and your patients, Jane, and good luck on spreading the word about your new book, *Inspirations: Stories of Breathing Better and Living Well*. Her book is now available at 877 BUY BOOK, as well as BarnesandNoble.com, Amazon.com, or Infinitypublishing.com. And contrary to the way it is listed, Mary Burns is NOT a co-author! Even big publishers like Amazon can goof and they certainly did this time! All the love and hard work that went into this book came from the efforts of *Jane*. Best wishes in the publishing world, Jane.

A donation was made to PERF by Tom Coen. Profile Structures Inc. made a donation to PERF in honor of Barbara Borak. Teri Neilson made a donation in memory of George Richey while James Lynch made a memorial donation to the Chair for C. William Treacy. Donations for the Chair were also made by Sylvia & Richard Vicker, and Ida Wilson.

*Jim Wood made a memorial donation to the Chair for his wife **Carlin** as did Mary Burns, Jeanne Rife, Reta Long, Al Giuntoli, Rolf & Mary Lee Dorff and Stan Sorenson. Carlin's name will remain in perpetuity on the plaque in the Clinical Trials Center as a **Supporting Member of the Chair in Rehabilitative Sciences.***

We would especially like to thank **Richard H. O'Hara & CO., Certified Public Accountants in Placentia, CA** for again waiving their annual fee to PERF. It is the many professionals who volunteer their time and expertise that help a small foundation such as PERF accomplish so much. This recognition of our value and good intentions is why we also receive donations from "insider" health care professionals such as **Denise Giambalvo, RN, MS** who just made another donation to the Chair. To these colleagues, and the many others who have given in the past, we are *especially grateful* for your recognition of what we are trying so hard to accomplish. Thank you!

Do you know who **Don Murphy** is? You do if you ever received one of the PERF booklets, because Don is the artist who did the illustrations as well as the beautiful covers. As the widower of one of Mary's rehab patients, Don has long been supportive of PERF and its goals to help those with respiratory disease. However, we recently learned that he also has *another* claim to fame. Have you ever been a boy scout, or had a boy scout in your family? If so, you probably have heard of the **Pinewood Derby**. Did you know that this is the brainchild of our own Don? Don started the original Pinewood Derby for his son's 1953 Cub Scout troop in Manhattan Beach, California. To his amazement he has learned that this event has grown to include *100 million Cub Scouts around the world!* Talk about leaving your mark on posterity!

Because of overwhelming interest in how this all started, Don was inspired to write a book called, what else, "**Pinewood**". This is an illustrated history with reproductions of original photographs taken during that first event in 1953. It includes the original rules and regulations, car plans, track design plus a "how to" promote and stage your own derby. Of course, knowing Don, it is no surprise that there are humorous anecdotes included as well as stories and lots of photos. Do you have a Cub Scout or troop leader in your life? If so, this is a great gift. The cost of Don Murphy's

colorful table book is \$14.95 plus \$4.00 p&h. Send the check or money order made out to: **PINEWOOD, P.O. Box 3881-E, Torrance, CA 90510**. Or write to Don by e-mailing: PWDfounder@aol.com. You also can check out his Website at www.nogreenbannans.com. (Yes, that *is* the correct address!) ☺☺☺

Are you a health care professional interested in "**CHANGING TIMES: The Future of Pulmonary Rehabilitation**"? If so, you are in luck! There is still time join other doctors, nurses, therapists and team members at the **California Society for Pulmonary Rehabilitation (CSPR) annual meeting at Long Beach Memorial Medical Center April 5th-6th**. This two-day meeting is *packed* with state of the art information delivered by world-class physicians, practitioners and scientists. *And* the price is right! Two full days of informative lectures and 11 CEU's is only \$150.00, if you are a member of CSPR. Add \$55 to that if you are *not* a member for what is still a total cost of \$205.00. How much does membership cost? Only \$55.00! Total cost? *Still only \$205!* Become a member and keep up to date on all the issues facing pulmonary rehab in these days of change. We have a block of rooms reserved at the Airport Marriott for only \$109 a night for single, double or even quad occupancy. What a bargain! For further information, or the brochure, e-mail Mary Burns at perf@pacbell.net or phone her at (310)

539-8390. We'd love to have you join us for what is always a fun, as well as informative, two days.

While Dr. Richard Casaburi has published hundreds of research papers, the one in Respiration 2001658-567-661 is special. It is the first publication that acknowledges, "RC is the Alvin Grancel/Mary Burns Chair in the Rehabilitative Sciences". Would you like to know more about this study? The first Author is Prof. Susan A. Ward of the University of Glasgow. We will try to give you a brief glimpse, in lay terms, of the 5-page article titled

"21st Century Perspective on Chronic Obstructive Pulmonary Disease"

The Abstract of the article, in part, reads: The prediction that chronic obstructive pulmonary disease (COPD) will be the third leading cause of death worldwide by 2020 has enormous economic repercussions. Yet many issues and questions remain unresolved. For example, how can population studies of morbidity and mortality be studied without a worldwide consensus on the definition of COPD? How can the early diagnosis of COPD be improved? Why is it that only minorities of smokers develop COPD, despite tobacco smoking being the primary risk factor? How can smoking cessation interventions be improved? To what extent are the pathologic changes in the

lung reversible-and, if so, at what stage? And to what degree is it appropriate to emphasize the similar features of COPD and asthma?

COPD has suffered from relative neglect as a topic of research compared, for example, to asthma. Several factors should change this. Death rates from COPD are skyrocketing. The era of thinking of COPD as a "disease of irreversible airflow obstruction" is over. New definitions of COPD stress that airflow obstruction is partially (though not fully) reversible, and acknowledge that inflammation plays a big role.

COPD is now considered a disease of addiction rather than of abuse and this makes the COPD patient a much more sympathetic figure. Various studies emphasize the importance of limiting environmental exposure to tobacco smoke for children as well as adults. This is especially important since there is a possibility that latent adenoviral (like the virus that causes head colds) infections can make lung inflammation from cigarette smoke worse.

Early diagnosis of COPD is a big priority. The pathological hallmarks of COPD are inflammation of the medium sized and small airways along with lung destruction. Recent research suggests that excessive mucus may also be linked to airflow limitation.

Exercise intolerance remains the subject of considerable debate and research. Is it shortness of breath or muscle fatigue that is the problem? We know that there are microscopic changes in muscle fibers. Is that because of corticosteroids, poor nutrition, low oxygen, and inflammatory mediators or just because of inactivity?

Current medical therapy for COPD is less than satisfying. For most patients, the mainstays of therapy are inhaled bronchodilators. Whereas inhaled corticosteroids have a firm place in asthma management their role in COPD is quite controversial. It is suggested that they may be useful in patients with moderate to severe disease to decrease exacerbations. Given orally for a serious exacerbation they decrease duration of hospital stays. Antibiotics also are of great use in blunting the severity of bronchitic exacerbations. Little is yet known about the long-term benefits of lung volume reduction surgery.

What are future needs? There is an urgent need for drugs that can control pulmonary tissue inflammation and destruction. What is the role of genetic susceptibility? Why do only a minority of smokers develop COPD when we know that smoking is the primary risk factor? To what extent is lung damage reversible and, if so, at what stage? The scientific community is starting to

focus on these questions. The answers cannot come too soon!

The Rehabilitation Clinical Trials Center at Harbor-UCLA is gearing up for a new set of research studies. This is the chance for patients with COPD to participate in state-of-the-art research projects that may help to develop new treatments for COPD. These studies are briefly described on a page attached to this newsletter. All studies provide compensation to participants. There are three studies getting started:

A study of a brand new drug which is hoped to decrease the inflammation associated with COPD

A study of a new inhaled bronchodilator. All participants in this study receive an exercise-training program; if it has been more than a year since you've been in a rehabilitation program, this is your chance to get a "booster dose" of exercise.

A study of the strength building effects of testosterone in women. The study in men was so successful, that we have a new grant to see if the effects are as good in women. (Those ladies who complained that they were being ignored, this is your chance to participate!)

You will find a flyer attached giving more specifics and telling you how to get involved *if you are in the Southern California area.* 😊😊😊

If we *have* heard from you in the past year, this message is *not* for you!. But, if we have **NOT heard from you, we need some help to clean up our records.** Yes, we know that we should send individual reminders that your subscription to the Second Wind is over due and, in the near future, we will start to do this. In the meantime we will send out this general appeal to those of you who have *not* communicated with us for more than a year.

If you find the Second Wind of help, we request a donation of \$20 a year to help us with our expenses. If you cannot afford the \$20 a year, but still wish to receive the newsletter, please send in a response saying you wish the Second Wind. We will be pleased to continue sending it BUT, we don't want to annoy anyone with unwanted mail! So, be sure to send in your response if you want the newsletter!

You may also read our newsletter by viewing it on our website at www.perf2ndwind.org. This site also contains other information of value and is in the process of being revised and *improved* by Dr. Janos Porszasz, who is the Technical Director of the Rehabilitation Clinical Trials Center at Harbor-UCLA.

We look forward to hearing from you and welcome all comments!

- Yes! I wish to receive the Second Wind. My check is enclosed.**
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