



March 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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Key words; COPD-A New Perspective, Breathin' Easy, Travel with Oxygen, Pulmonary Fibrosis, Finding a doctor, research opportunities.

A belated Happy St. Patrick's Day to all our friends and readers! We may be a few days late, but even if you are not a descendent of the Emerald Isle, we would like to send you an

IRISH FRIENDSHIP WISH

May there always be work for your hands to do;
May your purse always hold a coin or two;
May the sun always shine on your windowpane;
May a rainbow be certain to follow each rain;
May the hand of a friend always be near you;
May God fill your heart with gladness to cheer you.

And who would be better than our half Irish friend, *Dr. Thomas O'Petty*, to start our newsletter this month discussing

COPD: A New Perspective

COPD affects 16 million people in the United States today. Probably an equal number of persons have undiagnosed disease. While pharmacologic agents used strategically along with pulmonary rehabilitation and oxygen in selected patients has improved both the length and quality of life, COPD is the only disease in the top 10 killers that continues to increase. In 1997 107,000 people died from COPD.

Projections for 2002 are that 115,000 will succumb. COPD costs approximately 30.1 billion dollars in both direct and indirect costs. Oxygen alone is responsible for about three billion dollars annually.

Today we recognize that the natural history of COPD covers 30 years or more. Most patients with early stage disease have no symptoms. One in five smokers develop COPD. Why most smokers do not get COPD is the subject of intense research efforts. Probably genetically based protective factors prevent the inflammatory damage to airways and the destruction of alveoli. About 15% of people with COPD are non-smokers. Accordingly, it is certain that the pathogenesis of COPD is multifactorial.

Early identification is key to changing the course and prognosis of COPD. Simple office spirometry can accurately diagnose and monitor COPD. New office spirometers are inexpensive, easy to use and durable. All primary care physicians should have an office spirometer, just like they have a sphygmomanometer, an EKG, or an ophthalmoscope and scales for patients' weight.

The National Lung Health Education Program (NLHEP), is a new health care initiative launched in 1997. The NLHEP enjoys a broad base of support from many societies, associations, governmental agencies and foundations. Financial support for the NLHEP comes from annual

unrestricted grants from the pharmaceutical and medical equipment industries.

"Test Your Lungs, Know Your Numbers" is the battle cry of the NLHEP. It is a "Call to Arms" for all primary care physicians and many specialists, such as cardiologists, to get involved in the diagnosis and treatment of all stages of COPD.

Why should pulmonologists support the NLHEP? The answer is simple. Pulmonologists do not see asymptomatic patients with COPD now. There are only about 10,000 pulmonologists in the USA, but 220,000 primary care physicians. *It is the primary care physician that sees the smoker each year in the office for something, that may or may not be a smoking related disease.* When primary care physicians identify patients in need of further evaluation, bronchoscopy, surgery, pulmonary rehabilitation and a wide array of specialized consultation, these patients will reach the pulmonologist.

Why should HMOs support the NLHEP? Again, a simple answer. COPD is a very expensive disease to treat in late stages, but not expensive in early incipient stages. Thus, even if patients switch between HMOs, the entire industry will save money if programs for the early diagnosis of COPD are implemented.

Why should industry support the NLHEP? Again an obvious answer. There is a huge market for a growing

number of products to serve the newly diagnosed patient.

Why should government support the NLHEP? For one, it is the right thing to do. Secondly, as the health of our nation improves, the quality and length of life will be enhanced.

A final challenge, and a major one, is to *increase COPD awareness*. We need a nation-wide patient advocacy group. We need the public to understand emphysema/COPD. We also need all stakeholders in COPD to recognize that smokers with airflow obstruction are also at a huge risk of lung cancer, heart attack and stroke, as we learned from the Lung Health Study. Thus, a nationwide COPD effort in early detection of COPD and in smoking cessation is truly a massive broad health care initiative for America.

We have a new perspective on COPD. We are entering a new era!

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All of us would like to extend our congratulations to **Dr. Petty!** **The University of Colorado** has just announced that the fourth Chair in the Pulmonary Division will be called the **Thomas L. Petty Chair in Pulmonology**. This Chair will be used to support a research scientist and will be funded in perpetuity. The first occupant of this Chair will be Dr. York Miller, Professor of Medicine at the University of Colorado who is doing his research on lung cancer. This is a very great honor and is

certainly well-deserved. Again, congratulations, Dr. Petty!

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WE GET MAIL

We'd like to thank **Joyce of Monroe, LA** for the lovely note she sent. You certainly don't owe your life to us, Joyce, but we are happy that we motivate you and give you hope. That's what we are aiming for, so thanks for the feedback! We also appreciate all those *other* nice notes we got from many of you along with requests that we continue to publish the Second Wind. You inspire us to continue our work!

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*Donations were made in memory of Carlin Wood by C.L. McGuire-Jones, and by Mary Haramoto in memory of George Haramoto. **The Alice Moore Memorial Fund** had donations by Mary Burns, The PEP Pioneers, C.J.Malley., Mr. & Mrs. Norman Parker, Delight & Bob Nease, and Frank Lynch*

Donations to PERF were made by Gerald Sandman, Linda Deighan, Virginia Elson, James Fraser, Ida Hinton, Jerry and Eleanor Gorby.

Gerry and Eleanor Gorby accompanied their donation and Second Wind renewal with the newest **2002 edition of Breathin' Easy** which features information about oxygen **concentrators** in addition to an update on all the contact **numbers you need to find oxygen when you travel anyplace in the US or the world.** At \$21.95 (\$28.60 including shipping and

tax), this book is essential for anyone who helps patients travel, or for the frequent traveler. For further information call Jerry at (888) 699-4360. Of course, you read everything that is in the book by accessing their web site at www.breathineasy.com. Why does Gerry do all this work and make so much of it accessible to you without charge? Because he has been a 24 hour a day oxygen user since 1995, Gerry knows all the frustrations and problems of traveling with oxygen. He is committed to doing something about it. Incidentally, he tells us that the 2001 edition of *Breathin' Easy*, with the special article on airlines, is as popular as this 2002 edition. You are providing a great service, Gerry. Thanks from all the oxygen users who are able to travel because of you!

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John Boynton made another donation to the Chair.

Kevin and Judy Hettich also made another donation to the Chair in honor of Mary Burns, as did Rose Bailey. (Thank you, my friends!) ♥ ♥ ♥

It was especially nice to get **Rose Bailey's** note "from the still frozen North". Those of you who have been reading the *Second Wind* for several years may remember the oxygen crisis several years ago that led to the Oxygen Consensus Conference and our national efforts to save liquid and portable oxygen. Rose is an oxygen patient who led the successful grass root uprising in Alaska that led to

saving portable and liquid oxygen in that wonderful state. A great group of people live up there, none better than Rose. Our best to all of you!

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Have you been trying to **find a pulmonary physician**? Here is *some* of the advice offered by **Wes**, who recently moved to North Carolina.

"I went to the **AMA** on the web at this site: <http://www.ama-assn.org/>.

At the top of their page, click on the block that says **DOCTOR FINDER**, then click on the block that says **SEARCH FOR A PHYSICIAN**. Read the **Terms and Conditions** and go to the bottom of the page and click **ACCEPT**. The next page asks you if you want to find a doctor by specialty or name. Click on **SPECIALTY**. Before you put in your city and state scroll to the bottom of the page and click on the words **SEARCH FROM AN EXPANDED LIST**. At the top of this new page, **put in your State and City but leave the zip code** out because many cities have 100 or more zip codes and you will miss a lot of doctors that way. Anyway, scroll down to **PULMONARY DISEASE** and click in the circle next to it. Then scroll to the bottom of the page and click **SEARCH**.

I found a gold mine. Over 20 pulmonologists in Raleigh and six of them were together in an office complex immediately adjacent to a hospital associated with Duke University.....Warm regards, Wes"

In checking this great site for Torrance, CA we found that it did not list all the local pulmonary physicians and did not specify that they were Board Certified, which is very important. Board Certified pulmonary physicians spent two or three years in an advanced study program (called a fellowship) and then passed a very difficult certification examination. There are several other web sites that you can check. One is for the American Board of Internal Medicine at www.abim.org. Look up the directory and specific city. It will list all doctors with this, and related subspecialties, such as Pulmonary Medicine. It will give you the date that they were certified and when that certification expires. It does not provide an address or phone number. While being Board Certified in Pulmonary Medicine does not guarantee the best doctor in town, it will mean that your physician has the right educational qualifications to care for your pulmonary disease.

If you do not have access to a computer, you can call AMIM at **(215) 446-3500**. You might also call your local **County Medical Association** for help. We hope you find this information of help and we really thank Wes for the footwork that he did.

Does it pay to call or write to the editor? You bet it does. **Tom**, from **Seattle**, wondered why we had so little information about **Restrictive disease** in the Second Wind. That is a good

question and something that had been of concern to your editor for some time. The truth is, there is just not that much information available about this complicated condition. Tom's plea spurred us to contact many University Centers that work with patients with different types of restrictive disease. We wanted to know what was new out there and what written information that might be suitable for the Second Wind. **Dr. Cecilia Smith at the University of California San Diego** promised to help us out. **Dr. Julie Woods**, who works with Dr. Smith, wrote the following introductory article for us.

Pulmonary Fibrosis is a chronic lung disease due to *excessive lung scarring* that usually affects individuals of middle age or older. It is an uncommon disease affecting approximately 70 people of every 100,000 as compared with asthma, which affects approximately 280 people of every 100,000. Often the first symptom noticed is a gradual onset of shortness of breath with exertion, accompanied by a dry cough. As the disease progresses, the scarring and inflammation within the lung causes increasing shortness of breath eventually leading to the need for oxygen. The disease progression can be rapid or very gradual, and varies greatly from person to person. Lung biopsies can sometimes help with the diagnosis, but the cause in some cases cannot be determined.

It is known to be associated with exposure to certain agents such as *asbestos*, but can also be associated with diseases like *rheumatoid arthritis*, or exposure to certain *drugs*. When a cause cannot be determined, the disease is called “*idiopathic*” **pulmonary fibrosis (meaning no known cause)**.

There is no known cure. Treatment includes steroids, which help decrease the inflammation and cytotoxic drugs (similar to drugs used for cancer) such as Imuran or Cytoxan (both taken orally), which help restructure the lung. Some patients respond to these drugs and are able to carry on a normal lifestyle, others, however, do not and the disease continues to destroy normal lung tissue. *Transplantation* may also be an option.

As with any chronic illnesses, it is extremely important to become well educated about the disease; *knowledge, emotional support and psychological counseling are the cornerstones of coping*. For this reason **Dr Cecilia Smith and Dr Julie Wood**, who run the **Interstitial Lung Disease Clinic at UCSD**, have started a regional support group in San Diego. These meetings are very interactive and focus on the sharing of information, feelings and solutions to problems. The meetings usually start with a coordinated short lecture on a specific topic with time for questions afterward.

For more information about these meetings please contact Julie Wood, M.D. at her E-mail address, jwmcclure@mindspring.com. In addition to being a transplant center, and having a support group, Dr. Smith has long had a list through which she tracks those with IPF (idiopathic pulmonary disease) and hopes to learn more about this condition.

We hope to have other articles on restrictive disease written for us by Dr. Wood in future issues of the Second Wind.

Another resource, for those of you wishing more detailed information about restrictive disease, is **The Coalition for Pulmonary Fibrosis** in San Francisco. Their informative web site is www.coalitionforpf.org. Mark Shreve is the Executive Director and can be reached at the toll free number of **888-222-8541**.

UPCOMING EVENTS

Do you live in the **Seattle** area? If so, you won't want to miss the **Round Table Discussion on Idiopathic Pulmonary Fibrosis** for physicians and patients on April 27th. Call Mark Shreve at 888-222-8541 for specific information. Many more such Round Table discussions are planned around the country in the next few months in cities such as Los Angeles, Chicago, New York etc. We will keep you posted in this newsletter when possible, but suggest that you call that

888-222-8541 number for specific dates and places.

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Were you one of the millions of people glued to the television set watching the Winter Olympics? We followed with interest the “blood doping scandal” of the disgraced Russian athletes. Not because of any morbid fascination, but because of the drug involved. How many of you noted that this drug, in addition to only being on the market for only a few months, was something that increased the athletes’ red blood cells, thus increasing their energy and exercise tolerance? Now, why do you suppose that increasing their red blood cells increased their energy and exercise tolerance? That’s right! It is because **the hemoglobin in red blood cells carries oxygen!** More red blood cells, means more hemoglobin, which means increased oxygen and energy. Does that sound interesting to you? Does it sound like something that might be of help to *you*, as well as those Russian athletes? Well, that is exactly the thinking of scientists at Harbor-UCLA. If it’s good enough for the Russians, it may be good enough for respiratory patients. Or rather, it’s the other way around, since this was being discussed as a possible help for those with pulmonary disease *months* before the Olympics. Anyway, under consideration at the Harbor-UCLA Rehabilitation Clinical Trials Center, is a major study on the effects of this drug on the exercise and energy level of patients with COPD whose red blood cell count is low. Are you

interested? Stay posted for more information on this study a month or two from now. (Olympic athletes not eligible.)

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LAST CHANCE to register for **CHANGING TIMES: The Future of Pulmonary Rehabilitation.** *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 costs only \$150.00. E-mail Mary Burns at perf@pacbell.net or call (310) 539-8390 today for further information.*

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Current News

Dr. Rich Casaburi had another paper published in the prestigious journal *Chest*, in which he is acknowledged as occupying the Alvin Grancel-Mary Burns Chair in the Rehabilitative Sciences. The first author is **Dr. Attila Somfay**, who was a visiting scientist at Harbor-UCLA when this study was done, but has now returned to Szeged, Hungary. The second author is **Janos Porszasz MD, PhD** who is our new web master. The name of the paper? I thought you would never ask. It is the “*Effect of Hyperoxia on Gas Exchange and*

Lactate Kinetics Following Exercise Onset in Nonhypoxemic COPD Patients". We won't attempt to give you a synopsis of *this* one! Just take our word that it is a contribution to the science examining the ways in which oxygen is of benefit to COPD patients who exercise!

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And speaking of **Dr. Porszasz**, he has been working long hours improving the look and the content of our web site, www.perf2ndwind.org. Won't you please take a look at it and tell us what you think? We really would like your opinion, since our goal is to give you as much information as possible in a way that you can easily access. If you are a patient we do hope that you will tell your physician or pulmonary rehab team about this site, since it should be helpful to them also. Our goal is to provide you with the newest articles on treating respiratory problems, or at least the abstracts of these articles.

We have started an additional feature, giving you a description of the **research studies that you can participate in**. Not only will you help yourself but you also will be helping others. Besides the possible benefits of the study itself, there is usually *very* generous financial compensation for your time. Now you do need to be aware that most of these studies, in order to have scientific validity, are double blinded and placebo controlled. That is, half of the participants get the treatment or the medication while the other half doesn't and no one, physician or patient, knows one from

the other. This gives an unbiased result. However, in all the years of working with patient research at Harbor-UCLA, I have never met a participant who didn't feel that it was worthwhile.

We have started by listing the opportunities at **Harbor-UCLA in Torrance, CA** but invite other universities to contact us in order to list the respiratory research that *they* are involved with. We would like to open this up to *all* of you across the country, as is part of the PERF philosophy. So, if you don't have access to the Internet, get a friend or relative to open it up for you. Telephone, write or e-mail us with your comments and suggestions. Our goal is to make this one of the most valuable sites on-line for respiratory patients *and* the health care professionals caring for them. Till next time, we leave you with.....

"The Irish Blessing":

MAY THE ROAD RISE TO MEET YOU,
MAY THE WIND BE ALWAYS AT YOUR
BACK
MAY THE SUN SHINE UPON YOUR
FACE
THE RAINS FALL SOFT UPON YOUR
FIELDS
AND, UNTIL WE MEET AGAIN,
MAY GOD HOLD YOU IN THE PALM OF
HIS HAND`

