



JUNE

2001

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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ATS, The American Thoracic Society, had its annual meeting in San Francisco this May attracting an international response of more than 17,000 physicians, researchers and others dedicated to solving the problems of pulmonary disease!

The languages may vary, but interests and problems are shared by all attendees whether they speak Polish, Swedish, Japanese or one of the many other tongues heard in the halls. Excitement filled the air as ideas were exchanged, new research reported, and friends from around the world greeted



each other with exclamations of delight.

If only each and every one of *you* could have joined this conference for an hour or two! You would have returned to your home filled with optimism for the future and no longer discouraged by what may seem like the world's lack of interest, or a lack of progress. Keep reading, and later in this newsletter we will give you a few of the highlights of this inspiring conference.



First, however, high on our list of priorities, is a last reminder about the upcoming **RALLY FOR RESEARCH** to be held at Long Beach Memorial Medical Center June 22nd starting at 9:30 a.m. (though most everything will be ready by 9 a.m. for our always

early rally participants!). If you have made an unanswered call to (310) 539-8390 please try again. Mary was out of the country and out of town for several weeks and a few calls may have been missed. We hope all of you who are planning to come make advance reservations. It is already obvious that we will have a capacity crowd and may not be able to handle last minute walk-ins.

Whether you are an individual, or coordinate a pulmonary group, getting your checks in early, rather than at the door, will help you to waltz right in, rather than standing in a long line. How? We will mail out a map, raffle ticket and name tag for each advance paying participant or group. The name tag with your name and group name is your admission ticket into the entertainment and displays that will be waiting for everyone. There is just too much to do and see to waste even a minute in a line!

Vendors who have not yet reserved a booth also need to contact us immediately to take advantage of displaying their products to such an interested audience while helping to support the Chair in the Rehabilitative Sciences. We still have 2 places open. Remember, your fee for joining us will go to support the Chair and will be

acknowledged as such. It is a win-win situation!



Speaking of financial support for the Chair, the friends and family of **Mary Nicolas Lynch** of St. Paul , MN continue to mail memorial donation in her name earmarked for the chair. The number of contributions, and the notes that accompanied them, impressed us with what a wonderful lady she must have been and what a great loss everyone must have suffered. The contributing friends adding memorial donations to last month's list are *Wm Bixby, The Frukcs, The Culligans, The Bradfords, The Lymans, Anne Deebes, Pat DeRosia, Virginia Wilkinson, the Andersons, Bartusch Brokerage, the Barnetts, Ralph Beauclair, Mike Benz, the Bernets, the Bettenburgs, the Billstroms, Jackie Borman, the Bumgardners, the Burkes, Bette Clifford, Willis Cline, Virginia Costello, the Crandells, Amanda Davis, the DeCosters, Susanne Delaney, Tom Dolan, Jon Duckstad, Dave Espe, Judge Faricy, the Fields, Judge Finley, Judge Flinn, the Fockes, Terry & Frank Lewis, the Fooshes, Mrs. Geisenhoff, R. Gersdorf, O.H. Godfrey, the Greelers, the Grubers, D. Heffermun, the Hoff's, the Hurds, Mrs. Husbands, Steven Jahnke, Scott Johnson, C. Joyce, the Klas', the Knudsons, D.*

Kolasa, Margolf C., Nancy Mason, the McMahons, the McQuillons, Judy Miller, the Mingos, Marjorie Naab, Ron Nagel, C. O'Brien, O'Gara's Reyne Rofuth, Mrs. Ryan, Julia Salman, the Slaters, the Summits, the Thompsons, Dr. & Mrs. Tregilgas, the Tschida, the Westlunds. and Meg McDougal. We know from your notes that this lady will live always in your hearts. We hope you, as well as others who have designated memorial donations for the Chair, receive some consolation in knowing that, thanks to your donation, your loved one will live in perpetuity as a Sustaining Member of the Chair in the Rehabilitative Sciences, helping others with respiratory disease.



The **Anaheim Huff & Puffers** made a donation to the Chair that truly touched Mary's heart. This is a group of 7 ladies who meet once a month to socialize, share and encourage each other. Thank you, ladies!



Carol Daly also remembered her friend *Ruth Lemker* by earmarking her memorial donation for Ruth to the Chair.



On that subject we have a letter from Dr. Petty.



PLEASE CARE FOR THE CHAIR

Dear Friends,

Now that there is a commitment to the newly established **Alvin Grancell/Mary Burns Chair in the Rehabilitative Sciences**, it is time for us all to dig deep and get enough money to fully fund the Chair. *This will be the first such Chair anywhere in North America.* With funding for new research into mechanisms of shortness of breath, fatigue and reduced quality of life for people with COPD and related disorders, we will develop new therapies. All this is happening at a time when the drug industry is actually designing new drugs that can deal with the basic inflammatory and destructive causes of chronic bronchitis and emphysema. In just a year or two we will have new treatment strategies, which promise to help the majority of people with COPD. *Our emphasis will also shift to early identification and intervention.* Already the **National Lung Health Education Program (NLHEP)** is being recognized as an important new health care initiative that will educate both the public and primary care physicians about new treatments for the only disease in the top 10 that is rising in this country today. All *other*

causes are going down as a direct result of research and new medical treatments.

The research that the new Chair will support will be a critical step in how we will be able to deal with COPD in the future. Please join me in making a second or third donation at this time. I have proposed the formation of **The Long Beach 500 Club**. *Membership for this Club is a donation of \$500 or more.* We have a growing number of members, some from your own doctors and friends. Give more, give less, but give what you can, so that we can continue to move forward.

I look forward to our forthcoming Rally on June 22. There we will review some exciting new developments in our understandings of what causes COPD, how it progresses, and how it can be better treated. The future is bright, but we need to all bask in the sunshine of success as we fully fund the Chair. *I care about this Chair and hope you do too.*

I'll see you at the Rally.

Your Friend,

Dr Tom Petty

On the plaque which will hang in the Clinical Trials Building, donations of \$500 will be listed as members of Dr. Tom Petty's 500 Club, *\$1,000 or more will be listed as **Sustaining Members***, those of *\$5,000 or more as **Premier Members*** and those of *\$10,000 or more as **Founding Members*** of **The Long Beach 500 Club**.

Gifts given earlier, in the initial drive, will be added to those given later so that you will get full acknowledgement for your total donations, and your status upgraded as appropriate. If you wish a signed acknowledgment of your standing in this very special club please let us know. We will be delighted to mail you a certificate suitable for framing.

Joining Tom Petty in the Long Beach 500 Club this month were, *Robert Chang, MD, Amy Walker, Jeanne Rife (in memory of her husband John), Reta Long, Eli Lilly & Co. Salter Labs. Chad Therapeutics, Inc. Pharmacia & Upjohn, Alvin and Jean Hughes, and Craig Murga.*



COPD is the 4th leading cause of death around the world and the only one which continues to rise rather than decline. Fifteen to 20 million Americans have COPD! Yet it receives the least research money of any of the major

diseases and far less than HIV, which gets the most research money, in spite of afflicting far fewer people in the United States. We *also* need more financial support and more outspoken advocates in fighting this disease. All of us thank those of you who give so generously to this neglected condition.

Here is our **roll of honor** to date. It will continue to be updated as more of you continue to join us, or to make additional contributions.

Founding Members

Alvin Grancell

Mary Burns

Sustaining Members

Fred Burdette

Richard Casaburi, PhD, MD

Thomas L. Petty, MD

Marjorie Dickenson

Billie Gaynor

The Margaret Gray Memorial

Emily Hansen

Keven Hettich

Little Company of Mary Sisters

Reta Long

Edmund Roth

The Mary Nicolas Lynch Memorial

Long Beach 500

Robert Chang, MD

John & Alice Moore

Jeanne Rife

Thomas Storer, PhD

Amy Walker

*Women's Fellowship of
Neighborhood Church
The Robert McDonald Memorial
Eli Lilly & Co.
Salter Labs.
Chad Therapeutics, Inc
Pharmacia & Upjohn
Metro-Med*

Mary Burns and Rich Casaburi also donated, to this special cause, the recent generous honorariums they received from the **Teijin Company of Japan**.

And speaking of Teijin, after the ATS conference in San Francisco several Japanese pulmonologists and representatives of Teijin, a company that supplies most of the oxygen in Japan, came to Torrance. Mary had the privilege of hosting them as they visited the area. Japan is committed to improving their oxygen service and the pulmonary rehab that they offer their patients.

They were very impressed with the two PR programs that they visited here in the Southland. The kitchen and laundry set up allowing patients to practice ADL's (activities of daily living) at Long Beach Memorial fascinated them. The high intensity exercise programs there and at Citrus Valley encouraged them to recommend more vigorous exercise regimes for their patients

in Japan also. Since one of the visiting physicians had many patients with restrictive disease they felt fortunate to see how successfully Cinda Claprod, RCP, coordinator of rehab at Citrus Valley, successfully integrated these patients into her regular rehab program. All the patients that our Japanese friends met at the PR programs warmly exchanged greetings with them while lauding their rehab programs and the positive changes it made in their lives. They also toured the Rehabilitation Clinical Trials Center at Harbor-UCLA and met with Dr. Richard Casaburi. He gave these visitors an update in the latest research activities in the Rehabilitation Center, where new applications for oxygen therapy are being investigated.

The exchange wasn't all one sided however. Our Japanese visitors showed us the **Oxy-glasses** popular with women in Japan. These are attractive glasses that cleverly conceal the oxygen cannula in the frames of the glasses. While this concept has been around for many years, their newest version was a big improvement on the older models. They also showed us a **wrist watch oximeter** made by Minolta. This small oximeter can store oxygen saturations for many hours in its memory making it a good

choice for overnight oximetry as well as exercise.

But perhaps of most interest to all of us was their **National Patient Society, "J-Breath"**, led by their president, **Mr. Fooyama**. He is also head of **Information Center for Pulmonary Patients** in Japan. Since he was a newspaper correspondent in Los Angeles for many years, he is a natural for this big job. Making use of his excellent English, he would like to share information with patient support groups in America. We have many sister cities with Japan here in California, why not sister patient support groups? Both Citrus Valley and Long Beach Memorial patient clubs are very interested in networking with him. Several patients at Citrus Valley are already exchanging e-mails with Mr. Fooyama, sharing common problems, ideas and tips that will help everyone, regardless of nationality or language spoken!

Would you or your group also be interested in such an exchange of ideas? Maybe you would be more interested in networking with patients in Poland, England, Sweden, Indonesia, Norway, Canada or Israel? We communicate with patients from these areas. Are you as excited about this idea as we are? This



could be the start of something big! How about it? If you are interested, e-mail us at perf@pacbell.net and we will see what we can arrange.

Have you ever heard that portable oxygen is going to the dogs? Well, it literally *is* in Japan! Is that bad? No, it is actually quite good as this picture of Mr. Fooyama and his charming wife and Oxy-dog prove. ***Oxy-dog?*** That's right.



Busy Mr. Fooyama came up with the idea. It is so successful that they have asked the government to give their Oxy-dogs the same status as that held by Seeing Eye dogs! And why not? We have a several other great pictures of a black Labrador happily pulling around a cylinder so this isn't the only Oxy-dog that is coming to the aide of oxygen patients. This isn't quite what we had in mind when we heard that the Japanese were working on a revolutionary portable oxygen system, but it sure is a lot more fun than another new piece of machinery!

Meanwhile, back to ATS. The importance of muscle dysfunction in lung disease continues to be an area of research, growing knowledge and growing importance. Can you believe that even a five or ten years ago very few of you, or your physicians, were aware that your muscles were affected by pulmonary disease? With many thanks to the pioneering work of Dr. Rich Casaburi and Dr. Andy Ries (both of whom will be speaking at the Rally), as well as other researchers, we have become aware of the importance of *muscle training* in helping you overcome the debilitating effects of lung disease. Studies continue in the area of high intensity exercise, pioneered by Dr. Casaburi, regarding the amount of exercise that results in the best result. The addition of testosterone , oxygen and various drugs to help attain the necessary levels of intensity are also ongoing in various studies. Keep reading this newsletter. In future months we will bring you the results of these studies, as soon as they are ready for publication, or when they start showing promise.

Strength training is also seen as being a very important addition to rehab. Again, the types and amount are still being



researched, but some important facts have come out of the studies already done. Some show sustained levels of strength one year after PR. There was also decreased hospitalization and increased survival in the groups that were followed. Patients in the supervised sessions did much better than those who elected for a home alone approach. Having a “drill sergeant” in charge of the exercise sessions also paid off in benefits for the participants.

Also under study are other approaches to exercise such as the intermittent high intensity-low intensity format. So what should *you* do while waiting to see which of these approaches is the best? Why, **keep exercising**, of course! What we probably will learn is that no one approach is best for everyone. What we *already* have learned is that in terms of decreased mortality and improved quality of life, it is *not* your FEV₁, it is *not* your age, **it is your level of activity that is most important!**

So, does that mean you need to train for the next triathlon?



300 feet in 6 minutes is

Absolutely not! We wouldn't think of discouraging you that way. **Just being able to walk more than**

associated with increased benefits and survival. So, all of you couch potatoes, paste *that* on your bathroom mirrors! Even a *little* bit helps, so start *today* by walking just a minute or so at a time, if that is all that you can do. Increase your time by only a minute a day at first. Now, you can do that, can't you? Get past that 300 feet mark and don't be a statistic. **Good luck!!!**

Lots of new medications are coming out, or are here already, for both COPD and asthma. Next month we hope to have room to cover some of them in detail.



If you enjoy our newsletter we remind you and your friends that you can also find back editions archived on our web site at www.perf2ndwind.org. Current newsletters get posted according to the time constraints of our web master.

If you would like a timelier edition mailed to you, we request \$20 a year to help with expenses. Make your check out to **PERF, PO Box 1133, Lomita, CA 90717**



Remember to Rally! Call (310) 539-8390 for information.