



APRIL 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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CSPR conference, NETT, End of life treatment, Support groups, Exercise with oxygen, Long term oxygen, Value of exercise testing, Exercise, Retinoic Acid (FORTE) study, Progress in COPD Research, EFFORTS Washington, DC Rally, LifeStyle concentrator

***D***o you sometimes wonder if there is enough interest in pulmonary rehabilitation and in helping those with pulmonary disease? If so, being at the **April 5th-6th annual conference of CSPR, the California Society for Pulmonary Rehabilitation** would have lifted your spirits. About 130 health care professionals gathered at Long Beach Memorial Hospital to exchange ideas, look at new



products, and listen to cutting edge lectures designed to help them understand and better serve their patients.

Kicking off the conference was internationally known **Dr. Andy Ries** giving an **Update on the NETT**. As you may recall, NETT stands for the National Emphysema Treatment Trial which is studying the effects of pulmonary rehab and surgery for emphysema vs. only pulmonary rehabilitation. In January, we published an article by Dr. Reis

about the study, to which you can refer. The results so far highlight the effectiveness of pulmonary rehabilitation as practiced widely in the medical community, not just at selected clinical and/or research sites. It is believed that rehabilitation is also an important adjunct to a surgical program like lung volume reduction surgery and plays an important role in assisting with patient selection as well as in helping patients prepare for, and recover from surgery. **Enrollment for the study ends at the end of this May so if you want to take advantage of this opportunity, act today!** It will be March of next year before the first paper about the results will be published, which is *record* time for such a study.

**Patrick Dunnne, Med, RRT, MPH** gave a lecture on **New Advances in Aerosol Therapeutics**, the science that allows delivery of drugs by inhalation. This lecture was so packed with technical information that we can't begin to summarize it. We plan to have an article written by Patrick, specific for our readers, on this important topic in the near future.

**Dr. Kenneth Landis** spoke on "Update on **Foregoing Treatment**", in other words, the bioethics of **end of life treatment**.

You may not realize how much attitudes have changed and improved over the last 10 years, though we still have away to go. Dr. Landis discussed some of the landmark cases that have helped clarify ethical and legal issues surrounding this subject of concern to all of us. He told us also that the **Advanced Health Care Directive replaces the Durable Power of Attorney for Health Care here in California**. Your *existing* Durable Power remains legal in California. However, it is wise for *everyone* in *all* states to check the legal status of their Living Wills, or other such documents, to make sure they will be honored. Laws vary from state to state. All of us wish to have some say in our own care and having one of these documents is the way to do it. Perhaps in the future we can have Dr. Landis write a longer article just for us but, in the meantime, there is good news for the future. California again leads the way. By the year 2006, in order to get a license renewal, a physician **must** have taken a 12-hour course in pain management and end of life care of the patient. This requirement is long over due and we hope to see other states emulate it.

**Jim Barnett, RRT** gave a very well received talk on "**Planting the Seeds of a Successful**

**Support Group**” which stimulated a lot of questions and discussion with the audience. He showed some great slides of his group on cruises and on his many trips to Laughlin where upper extremity exercises were practiced on the slot machines. Unfortunately, none of these hour-long talks were recorded. We can’t reproduce the slides that Jim showed of his active support group, but, should you wish detailed information on starting or improving your *own* support group, we do have a suggestion. Mary Burns has written several chapters on this subject. The medical librarian at your local hospital should be able to get the following references for you.



**Burns M. Continuing Care Programs. In: Casaburi R, Petty TL; eds. Principles and Practices of Pulmonary Rehabilitation. Philadelphia: Saunders, 1993;pp 398-404.**

**Burns M. Social and recreational support of the pulmonary patient. In: Hodgkin J, Connors G, eds. Pulmonary Rehabilitation: Guidelines to Success, 3<sup>rd</sup> ed. Philadelphia: JB Lippincott, 2000**

For further information you can

also call Jim at (877) 280-2777 or Mary at (310) 539-8390. Support groups are very important!

**Margareta Emtner, PT, Ph.D.** told us about “**Supplemental Oxygen in Rehabilitative Exercise Training in Non-hypoxemic COPD Patients**”.

What does that mean? In lay terms, this study found out what happens when patients whose lowest saturations with exercise are above 88% participate in an exercise-training program while receiving supplemental oxygen. In theory, these people don’t “need” oxygen. This is a study that was recently completed and the data is still being worked on.

Margareta, who did this research at Harbor-UCLA as a Fulbright Scholar last year, will present the completed data at the European Respiratory Society annual meeting in Stockholm next September. We’ll give you more of the details then, but in the meantime, it may not surprise you to learn that yes, oxygen does help COPD patients exercise harder and longer even though they don’t “need” oxygen. Interestingly enough, a previous study showed that people *without* COPD *don’t* improve their exercise ability with oxygen, in spite of what those football players may think!



What does this mean for

you? Maybe in the future rehab programs will *start* their patients exercising the first few weeks of rehab with oxygen, even if they don't "need" it, to give them a jump-start, making it easier to achieve a routine of exercise. Stay posted and we'll give you more information on this interesting subject later.

**Dr. Rich Casaburi** gave a companion lecture to Margareta's titled "**The Scientific Foundations of Long Term Oxygen Therapy**" in which he gave a wonderful lecture on the physiological effects of oxygen, what determines an exercise training response in COPD, and how oxygen supplementation affects this. Rich made the point that oxygen is a miraculous "drug", providing a number of beneficial effects. He discussed in detail the benefits of high intensity exercise, and how oxygen supplementation would be expected to allow higher exercise intensity

**Janos Porszasz, MD, Ph.D.**, our web master, spoke on **Clinical Exercise Testing**. Using case studies as examples, he explained how the heart and lung often interact to cause shortness of breath, low oxygen levels, abnormal blood pressure and various cardiac responses.

Knowing all of these interactions can help the pulmonologist to better evaluate a patient's shortness of breath.

**Christopher Cooper, MD and Tom Storer, Ph.D.** gave companion talks about **exercising patients with COPD**.



Dr. Storer focused on strength training, which is just beginning to be stressed in rehab programs. It is important to start out slowly and very gradually to build up endurance and strength. While he did not discuss it in his lecture, Dr. Storer has developed a very successful exercise maintenance program for pulmonary patients at El Camino Community College, in Torrance, CA. If you would like more information on how to get such a program started at your community college, or would like to discuss this further with Dr. Storer, he can be reached at **(310) 660-3667** or by e-mail at [tstorer@elcamino.cc.ca.us](mailto:tstorer@elcamino.cc.ca.us).

Or, if you would like to read their lectures in full, ask the medical librarian at your hospital for the **supplement to Medicine & Science in Sports and Exercise, Volume 33, number 7, July 2001.**

**Dr. Paul Selecky** gave his usual informative speech on "**Sleep in Patients with Lung Disease**" that had everyone doubled over laughing. A talk by Dr. Selecky is best of all worlds when you are

approaching the end of 2 days crammed full of information! We feel that this is such an important topic that we have asked Dr. Selecky to write an article on this subject for a future Second Wind rather than just give you the brief synopsis space would allow today. It is worth mentioning that, later that same day, Dr. Selecky was presented an award as **Man-of-the-Year** by the American Lung Association of Orange County. Congratulations, Dr. Selecky! That is a well-deserved award!

This CSPR Conference was a smashing success! Plans are already underway for a repeat performance next April in Sacramento. While several states outside of California were represented at Long Beach, it is hoped to make this a truly *regional* conference, specific to pulmonary rehabilitation, next year.



**WE GET MAIL**

*PERF received donations from William Gustafson, Freda Standeford, Sharon Foster, Bill & Shirley Grindrod, Wesley Shull, and Gladys Mollison. .*

*Dr. and Mrs. Richard Casaburi made another very generous donation to the Chair in the Rehabilitative Sciences.*

*Sam Carlson, Sally & Wiley Conover and Leah Lindquist all*

*made donations to the **Alice Moore Memorial Fund.***

**RETINOIC ACID (FORTE) TRIALS**

**Who is Alice Moore?** Alice and her husband John went through Mary Burns' pulmonary rehab program many years ago, and have been very supportive of PERF, and all it stands for. But probably of more interest to all of *you*, Alice was *the first person* to go through the **Retinoic Acid (Vitamin A) Trials.** Did you know that it was because of the perseverance, and financial commitment of John Moore that these studies, so successful in the rat, were adapted to mankind? John feels that Alice's participation in this study prolonged her life.

The initial pilot program was set up by Alice's pulmonologist, **Dr. Michael Roth at UCLA.** As you know, NIH felt that the results were promising enough to warrant the investment of substantial funds by extending the program to other Centers around the United States. **Admission of patients into this study will end in June.**

The following letter from Dr. Roth was written for physicians but we feel it will be of interest to all of you.

"Until recently, it was believed that emphysema is an

irreversible and progressive process. However, in 1997, an animal model demonstrated that all-trans retinoic acid (ATRA), a vitamin A derivative, could reverse the damage associated with emphysema and regrow new functioning alveoli (Nature Medicine, 3(6):675-7). A pilot study was conducted and confirmed the feasibility of treating patients with this compound (Am J Respir Crit Care Med, 165:718-723, 2002). Expanding upon this exciting discovery, we helped the NIH/National Heart, Lung and Blood Institute develop a multi-center pilot study called the FORTE Study (Feasibility of Retinoid of Therapy for Emphysema). This is a randomized, double blind, placebo-controlled trial designed to measure the safety, tolerability and clinical/biological impact of ATRA (Vesanoid) and 13-cis retinoic acid (Accutane) on patients with emphysema. These medications are already FDA approved for other indications, though neither is approved for the treatment of emphysema. Outcome measures for this trial will include pulmonary function tests, CT scans, bronchoscopy with BAL for biomarker analysis, and quality of life questionnaires. This research examines an entirely new approach to treating emphysema.

We are in the last 6-months of recruitment and are looking for patients, ages 45 and older, with physiologic (FEV1 between 25 to 80% predicted, DLCO < 80%) and radiographic evidence of emphysema (>10% lung involvement by CT). The study is designed with a crossover phase so that every patient who participates will be treated with one of the active medications. Active medical issues, such as unstable angina, renal failure, steroid-dependent lung disease, or ongoing smoking are exclusion criteria. Other than the cost of the initial screening visit (which can be waived depending upon financial conditions), all medications, tests and visits are covered by the study and \$500 in compensation will be provided to offset the subject's time and effort for participating. If you are interested, please contact one of us or our study coordinators, Grace Ibrahim and Francine Estrada, at these numbers.

**(310) 206-7389**

**(310) 267-2020 (FAX)**

If you would like any further information on the rationale or design of the study, please feel free to contact me or visit our Website: <http://www.lung.med.ucla.edu/Clinical%20Research/FORTE/>

Many thanks for your help in advancing the study of this new

treatment,

*Michael D. Roth M.D.*

*Principal Investigator*

*UCLA IRB#: 99-04-057-03C -  
notice approved Oct 11, 2001*

Developed and funded through the National Heart, Lung and Blood Institute of the National Institutes of Health, the FORTE Study will enroll a total of 300 emphysema patients at 5 clinical centers across the country (60 patients at each site):

- UCLA School of Medicine
- UC San Diego School of Medicine
- Boston University School of Medicine
- Columbia University and Long Island Jewish Medical Center
- University of Pittsburgh.

*[Those of you outside of the UCLA area may call the above closest listed hospital for further information on joining this study.]*

We've reviewed the paper that resulted from the first group of patients to receive retinoid acid, published in the American Journal of Respiratory and Critical Care Medicine just last month. In this small group, no beneficial effects on lung function were detected.

However, we are all anxiously awaiting the results of the larger study!

### **CURRENT NEWS**

**Good news about progress in COPD research** was relayed by

our very own **Dr. Rich Casaburi**. He was one of about 20 invited participants at a meeting held in Bethesda, Maryland last month. The meeting was organized by the **National Heart Lung and Blood Institute, the division of the National Institutes of Health that has the responsibility to oversee government support of research in lung diseases**. The meeting specifically discussed new initiatives in clinical research in COPD. The participants were encouraged to "think big" about research projects that might result in improved treatment options for COPD patients. A major topic of conversation concerned new approaches to prevent COPD patients from getting sick ("having exacerbations")...usually related to lung infections. Also discussed were strategies for early detection of disease, which might include such measures as early spirometry or perhaps genetic testing to determine which smokers are predisposed to develop COPD. Studies to clarify the indications for oxygen therapy were discussed. Establishing a network of research centers that could collaborate on

large-scale therapeutic trials was another concept that seemed to have support. A report of this meeting's findings will be composed and should be in print next year. The ability to get government grants specifically targeted at COPD-related issues should be enhanced. *This can only be good news for the COPD community!*

### **Future Events**

**EFFORTS** (Emphysema Foundation For Our Right to Survive) is holding their **3rd Annual Rally for COPD Awareness on May 6, 2002 in Washington, on the west lawn of the White House.** Gary Bain, the President of EFFORTS, invites all of you to join them. For detailed information on the planned events, see their web site at <http://www.emphysema.net/3rdrally.html>. You may learn more about EFFORTS on their web site at <http://www.emphysema.net>.

Several companies are working on smaller more portable oxygen concentrators. However, **AirSep** has just announced that the FDA has approved their **LifeStyle, a concentrator that weighs less than 10 lbs. (4.5 kg)** and offers several increased portability options, including a fully retractable cart and a multi-battery pack

for added mobility. The unit's patient interface area, with easy-lift cover, provides flow setting options up to an equivalent of 5 liters per minute and visible, as well as audible, patient safety alarms. LifeStyle continuously produces its own supply of therapeutic oxygen with a pulse-flow delivery on every breath. ***Continuous flow is not yet available, so oxygen saturations should be tested with use as with all conserving devices.*** The unit is powered by AC household electricity, a DC automobile adapter, or a rechargeable battery pack. For further information, contact **AirSep Corporation. Tel: 716-691-0202, Toll-free: 800-874-0202, Fax: 716-691-4141**

**ATS, The American Thoracic Society,** will hold its annual international meeting in Atlanta, Georgia next May 17<sup>th</sup> through the 22<sup>nd</sup>. Just listing the details of each available lecture produces a book larger than most telephone directories! We can't bring you up to date on everything presented, but we will try to present some of this cutting edge information on the treatment of pulmonary disease. Watch for the next Second Wind, early in June, for more interesting information.

Until then, stay well and keep exercising! ☺☺☺