PULMONARY EDUCATION AND RESEARCH FOUNDATION

An International Organization
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Annual Report and Request for Your Support

We send our warmest holiday wishes. We hope your year has been happy and healthy. PERF, the Pulmonary Education and Research Foundation, has had a very busy year and we welcome this chance to bring you up to date.

First, the best news of all. Dr. Tom Petty, Emeritus member of our Board of Directors is back in the saddle after a serious illness. We appreciated the irony that, having been the single individual most responsible for the establishment of oxygen therapy in the United States, Tom found himself needing oxygen therapy himself. Characteristically, when given lemons, Tom made lemonade...authoring a book titled “Adventures of an Oxy-phile” to describe his experiences and the experiences of others who find themselves needing oxygen therapy. I’m happy to report that Dr. Petty is back to enjoying things he loves most...contributeing to the science of pulmonary medicine and fishing (not necessarily in that order).

Mary Burns, the heart and soul of PERF, has been much in demand. She’s just returned from two weeks in Japan and China. In Japan she spoke to several groups about pulmonary rehabilitation. The Japanese have made wonderful progress in recent years in adopting many of the rehabilitation strategies we have been promoting, and are well under way in making state-of-the-art oxygen therapy widely available. Mary is already booked for an extended visit to her colleagues in Norway. Since their visit at mid-year, she has been spending time working on a three-way interaction with Norwegian rehabilitation experts and practitioners in Russia who are struggling to begin to introduce rehabilitative techniques. PERF is considering expanding its reach and beginning a program that will allow practitioners from countries in which rehabilitation is poorly developed to study with us for a year. In several cases, we have seen that individuals who have spent time with us have gone back to their home countries and made a real impact on pulmonary rehabilitation practice.

We’ve been involved in educational activities closer to home, as well. We had a wonderfully successful “COPD Alpha-1 Education Day” in October. This was a full-day meeting with over 130 attendees. Nine lecturers presented two lectures each: one aimed at the patient attendees and one for the health care practitioners. Co-sponsored by the Alpha-1 Foundation, this free event was appreciated by all, but most especially by the rehabilitation patient club members who were bussed in from all over the Los Angeles basin. On a National level, I was pleased to Chair a symposium at the American Thoracic Society annual meeting in May that was titled “Cutting Edge Controversies in COPD Rehabilitation: A Pro-Con Approach”. This was a wonderful session, with the pick of the world’s rehabilitation experts debating important issues in pulmonary rehabilitation.

Of course, the key to our educational activities continue to be our award-winning newsletter and website. Dr. Janos Porszasz continues to keep our website (www.perf2ndwind.org) modern and easy to navigate. Mary Burns not only dispenses her wit and wisdom monthly in the newsletter, but also spends much of her time answering questions from troubled patients and their families from near and far. A mid-year purchase of modern printing equipment means that we save printing costs and have been able to upgrade our graphics to full color.

We’ve welcomed two new members of the Board of Directors of PERF this year. Dr. Janos Porszasz has been Webmaster for the past few years. He is a native of Hungary, but has been the mainstay of the research effort in the Rehabilitation Clinical Trials Center for 5 years. Mr. James Barnett heads the pulmonary rehabilitation program at Mission Viejo Medical Center. He has been very active on a statewide basis in promoting rehabilitation and is past President of the California Society for Pulmonary Rehabilitation.
We also, with regret, accepted the resignation of Jeanne Rife from the PERF Board. Jeanne has served as Board Secretary for many years. Her service and friendship are most sincerely appreciated.

Alvin Grancell, Vice President of the PERF Board, continues to amaze us with his ingenuity and generosity. Seeking to make the Alvin Grancell/Mary Burns Chair in the Rehabilitative Sciences fully functional, he has recently made arrangements that will unequivocally allow a physician scientist to devote full time to rehabilitation research. While others have made contributions toward the Chair fund, Mr. Grancell is by far the biggest donor. This Chair will operate in perpetuity! We see the effect of this endowed Chair stretching into the distant future. There will always be a scientist at the Los Angeles Biomedical Research Institute at Harbor-UCLA Medical Center who will carry the title of the Grancell/Burns Chair in the Rehabilitative Sciences.

We are increasingly active in public policy related to pulmonary medicine. Dr. Brian Tiep, an original member of our Board of Directors, was a prominent contributor to the new international guidelines on management of COPD. Dr. Tiep, Mary Burns and I have also been heavily involved in home oxygen policy. We contributed to a position paper that is aimed at reforming the way in which oxygen is reimbursed by Medicare and allowing expanded access to modern oxygen supplies. I was an invited participant in a National Institutes of Health workshop charged with identifying gaps in our knowledge concerning the way home oxygen is used. We are likely to see more government funded research into oxygen therapy in the near future.

The Rehabilitation Clinical Trials Center is humming with activity. Our little band has grown to five investigators, five study coordinators and a visiting scientist from Japan. We’re expecting visiting scientists from Thailand and Hungary in the coming year. Our most prominent research project continues to be involvement in the COPD Clinical Research Network, a large multicenter group funded by a 5-year grant from the National Institutes of Health and charged with finding new therapies and perfecting existing therapies for COPD. The first project, which our group designed, explores the benefits of lightweight oxygen in promoting a better lifestyle. A second, and much larger, project involving over 1000 patients will study the ability of drug therapy to reduce the frequency of COPD illnesses.

We must be fundraisers to continue our work. Barbara Borak, a valued member of our Board of Directors, hosted a very successful fundraising event at her elegant home in October. Her guests were entertained by a musical program; musicians included our own highly talented Dr. Brian Tiep and his daughter Rebecca.

We ask for your support. This is our annual appeal; the only time you will be solicited. I can assure you that your donation will be used efficiently to promote research and education into advances in pulmonary research and education. We really know how to squeeze every last cent out of your dollars! All of our Board members contribute their services. The legal services needed to run our Foundation are generously donated by a member of our Board, Mr. Peter Pettler. Our accounting services are also donated.

Your donations are fully tax deductible and will be gratefully acknowledged in writing. We hope to hear from you.

We wish you and yours all the best for the holiday season and wish you a healthy New Year.

Sincerely,

Richard Casaburi, Ph.D., M.D.

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Alvin Grancell/Mary Burns Chair in the Rehabilitative Sciences
Medical Director, Rehabilitation Clinical Trials Center
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