

PULMONARY EDUCATION AND RESEARCH FOUNDATION
An International Organization



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Annual Report and Request for Your Support
November, 2008

We wish you all the happiest of Holiday Seasons. We have a lot to be thankful for. We hope this letter finds you and yours happy and well.

As I write this, I am winging my way back from Shanghai, China. In the last few weeks I have received a full lesson on the progress that is possible in pulmonary rehabilitation around the world. I've visited two countries, China and Poland, whose health care system (at least in the large cities) is quite advanced. Yesterday I toured a 900 bed hospital in Shanghai devoted entirely to pulmonary disease; it was almost brand new and very well equipped. I visited similarly advanced hospitals in Beijing. In Poland, I spoke to high-level Polish pulmonary experts. In these countries, pulmonary rehabilitation is unavailable and almost unknown. I gave seven lectures in six cities, each emphasizing what pulmonary rehabilitation can do. I came away with a large number of contacts of people interested in learning more. In contrast, I lectured in Japan last week. When I first lectured on pulmonary rehabilitation almost ten years ago, pulmonary rehabilitation was virtually unknown. Today it is widely available and Japanese scientists are making a major contribution to pulmonary rehabilitation research.

Great strides are being made here at home, as well. Last year, I reported to you that a major battle was underway that would determine the future of pulmonary rehabilitation. Buried within the gigantic Medicare bill that passed Congress and was signed into law last summer was a provision establishing a pulmonary rehabilitation benefit for Medicare recipients. It is hard to overstate what a huge victory this is. Funding of pulmonary rehabilitation has always been a tricky task, with rules set regionally; in some regions of the country it was almost impossible to cobble together sufficient support for programs. This new law means that by 2010 a detailed national policy will be composed for funding pulmonary rehabilitation under Medicare. A coalition of lung organizations supported the effort to promote this legislation. The COPD Coalition (of which PERF is a member), linked to the Congressional COPD Caucus (a group of like-minded Congressmen and Congresswomen), spearheaded the effort. Dr. Vlady Rozenbaum, a member of the PERF Board who lives in the Washington area, was a major contributor to this effort.

The Rehabilitation Clinical Trials Center (RCTC), the laboratory that Dr. Janos Porszasz and I direct at the Los Angeles Biomedical Research Institute at Harbor UCLA Medical Center, continues its mission of promoting COPD research. Our most recent research fellows have come from China, Japan, South Korea, Taiwan and, of course, right here in the USA.

As I explained last year, an ambitious new project is the COPD Gene study that proposes to find out what in our genetic makeup distinguishes the unlucky 25-30% of smokers who develop COPD from the lucky 75-80% who don't. The COPD Gene study aims to study about 11,000 people and to look at their *entire* genetic structure. We'll compare smokers who have COPD to smokers who do not have COPD to see how they differ genetically. This approach seems fairly certain to define defects in the lung defenses of COPD patients – and to suggest new therapeutic approaches. The National Institutes of Health is funding this study and it is being

performed at 17 sites around the USA. It is our target at the RCTC to recruit over 800 patients over a 4-year period...this means recruiting one new person every working day! We started work in April and much to our credit of Carmen Lopez-Garcia, the lead study coordinator on this project, and Mary Burns, our star recruiter, we are right on track with about 110 subjects recruited so far.

Our most exciting new study involves stem cell therapy; very few reputable studies of stem cell therapy as a treatment for human disease have been attempted. We worked very hard to become one of a handful of sites to be the first to attempt to utilize stem cells to treat COPD. At our center, a dozen or so hearty volunteers are receiving several months of monthly stem cell infusions created from the bone marrow of health volunteers. This early study seeks early evidence that this approach is safe and may benefit the lung. We hope that bigger studies will follow.

Our large multi-center NIH-funded study of the benefits of oxygen therapy has been slow to get underway, but is about to begin. We will determine whether COPD patients with less severely low oxygen levels than those we currently treat benefit from long-term oxygen therapy. To do this, 3200 COPD patients (250 at our center) will participate in a 5-year study. We've recruited investigators at four other sites in the Los Angeles area who have agreed to collaborate with us to accomplish this task. Among them are PERF Board members Dr. Brian Tiep at the City of Hope and Jim Barnett at Mission Viejo...it's good to have friends!

The NIH-sponsored COPD Clinical Research Network is entering its sixth year of operation and continues to be a major research focus. There are three studies now underway; a fourth study testing the ability of statin drugs to help heart and lung function in COPD patients is about to get underway.

We are working to address a major factor limiting our productivity. Again, our Vice President, Alvin Grancell, has agreed to help. We need another physician/scientist to share the work load with me so we can take on even more research. Alvin has agreed to provide critical funding to help support this recruitment. This will supplement funds that our institution and our laboratory have agreed to provide. Thanks so much, Alvin!

Dr. Tom Petty, has just published his autobiographical book, "'From the Other End of the Stethoscope'", available soon. Tom's devotion to those with pulmonary problems has never faltered. He has had another tough year, with numerous health problems holding him down. His strength of spirit remains an inspiration to us all.

Chris Garvey, FNP, MSN, MPA, has become an important member of PERF in a short time. Chris has long had a national presence as a leader in pulmonary rehabilitation practice and now shares her valued expertise with us. She publishes an excellent newsletter; we plan to distribute it through the PERF website (perf2ndwind.org).

Rubye Richey continues to be invaluable as our patient representative spreading the word about PERF to other patients and offering her personal insights.

Vlady Rosenbaum PhD also offers us his views as a patient on oxygen while continuing a schedule that would shame the most healthy of us. He manages his important on-line patient support group, COPD-alert (COPD-alert.com), keeps all of the PERF board informed of the latest legislation, testifies to Congress and is active in many organizations. You are amazing, Vlady

Our own Mary Burns still has ulnar nerve problems, which make computer work difficult and prevent her continued editing of the Second Wind. However, she has kept busy hosting visiting fellows of the Rehabilitation Clinical Trials Center. She delights in showing visitors from foreign lands how rehabilitation works. In recent years we've sent a troop of research fellows back to their home countries to establish pulmonary rehabilitation programs.

Dr. Brian Tiep has been continuing his innovative ways at the City of Hope Medical Center. He is continuing his research in pre-operative rehabilitation for those needing lung cancer surgery. Working with surgeons who employ robotic surgical techniques, he intends to define the optimal way to bring people through their challenging time.

PERF couldn't get along without Dr. Janos Porszasz. He manages our website, sends out e-news, while continuing his supervision of the clinical trials center. Thank you, Janos

Jim Barnett continues to improve the lives of people participating in his world-class pulmonary rehabilitation program at Mission Viejo Medical Center. His group is participating in a groundbreaking study of bronchial valve insertion for the treatment of patients with emphysema.

I need to acknowledge the work of three members of our Board, whose contribution is vital to our function. Jean Hughes, our treasurer, has been keeping our books straight for over 20 years. Barbara Borak contributes fund raising ideas. Peter Pettler provides the legal expertise that keeps our corporation on the straight and narrow.

As you likely know, PERF conducts only one annual appeal; this is the only time you will be solicited. We ask for your donations that will directly support our work in promoting research and education in the fields of rehabilitation and COPD science. We can promise that your donations will be used efficiently. All of the Board of Directors contribute their services without compensation.

Your donations are fully tax deductible and will be gratefully acknowledged in writing. We look forward to hearing from you.

We wish you and yours the best for the holiday season and for a healthy 2008.

Sincerely,

A handwritten signature in cursive script that reads "Richard Casaburi".

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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