

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 productive year and we welcome this chance to bring you up to date.

As we look back over the past few years, we realize that one of the most tangible ways in which we'd advanced the cause of COPD therapy in general and pulmonary rehabilitation in particular is in training rehabilitation scientists and researchers. In the past years we have welcomed scientists from Hungary, Japan, Korea, Sweden, Brazil, Thailand, Taiwan, Iran and China as well as from our own country to spend time (usually a year or two) in our laboratory, learning what we have to teach. All have returned home carrying the message; some have established their own research programs. We've learned with pride that Dr. Attila Somfay, who earned his research doctorate while working with us way back in 2001, is now the President of the Hungarian Respiratory Society – effectively the lead lung doctor in Hungary. More recently, Dr. Evan Chang returned to Taiwan to establish a facility where exercise sciences and pulmonary rehabilitation collaborate. Some of these individuals have come with funding from their home institutions. But, for some, this is only partial support; others have not been able to come for lack of funding. In recent years, we've been able to support some of these scientists with PERF funds in the form of the Alvin Grancell/Mary Burns Visiting Scholar in Pulmonary Rehabilitation (named in appreciation of the initial contribution to this fund). In the past year, Alvin Grancell has agreed to make a standing contribution to this fund so we can have a reliable source of support for our Visiting Fellows. Thank you, Alvin!

I send you greetings from Mary Burns who, despite repeatedly stating intentions to “slow down” is the eternal “Energizer bunny”. She has helped us with recruitment in our research studies. She has been a wonderful hostess for “dignitaries” from near and far who visit our laboratory. Most recently, Dr. Jenny Alison from the University of Sydney has been visiting; Mary has committed to giving her a tour of area rehabilitation programs. Please visit our website at perf2ndwind.org if you haven't lately; see what new postings our webmaster, Dr. Janos Porszasz, has provided.

For those of you who know Dr. Tom Petty, our mentor and role model...and the man who founded the field of pulmonary rehabilitation, I wanted to provide an update. Dr. Petty has had a difficult year, with health problems slowing him down considerably. I knew that things were looking up when he wrote asking that I contribute to a new book that he had decided to write; Mary Burns has agreed to contribute, as well. Titled “Further Adventures of an Oxyphile”, this book will explore the usefulness of oxygen therapy both from a scientist's and a user's point of view.

The biggest news in the field of pulmonary rehabilitation this year is the coming initiation of rehabilitation funding as part of Medicare. For the first time, there will be a stable funding base for programs; previously funding had to be stitched together and in some regions of the country it was effectively impossible to finance an ongoing program. In Southern California we've been lucky to have a number of excellent programs, but we are the exception rather than the rule. Starting on January 1, 2010 the Medicare funding will begin. The startup has not been without difficulty,

however. It is up to the Centers for Medicare and Medicaid Services (part of the Executive Branch of the Federal government) to set up the funding mechanism. The first draft was awful! It would have been much worse than the existing situation. A strong effort by rehabilitation professionals and patient advocates, respectively including our own Chris Garvey and Vlady Rosenbaum, resulted in a much improved second draft. We're on our way!

As the occupant of the Grancell/Burns Chair in the Rehabilitative Sciences, I've had a frenetic year of travel, lecturing about COPD and about pulmonary rehabilitation as I go. This year I passed the million-mile lifetime mark on United Airlines; I've flown more than 100,000 miles in each of the past five years. In addition to over 30 lectures in the United States, I've given lectures in Italy, Spain, Austria, Poland, New Zealand, Australia and Columbia this year. As I've traveled, it has been gratifying to see the growing interest in both COPD and rehabilitation. My proudest accomplishment in many a year was to compose a paper (with Dr. Richard ZuWallack) titled "Pulmonary rehabilitation for the management of chronic obstructive pulmonary disease". This paper was published in the New England Journal of Medicine, the world's highest impact medical journal. It was a pleasure and a privilege to summarize the impact that pulmonary rehabilitation has had on medical practice. If you'd like a copy of this paper, I'd be glad to send either a paper or an electronic copy, please contact me (at PERF's address or by e-mail at casaburi@ucla.edu).

We have had another banner year in our research laboratory, the Rehabilitation Clinical Trials Center. Dr. Janos Porszasz and I lead a staff of more than a dozen research associates, study coordinators and visiting scientists. But none of our efforts would succeed without patients with lung disease who volunteer to be "poked and prodded" in the interest of advancing research. Our research participants become our friends; we could not succeed without them!

We've committed to a heavy load of research projects; we have more work than we can handle! Here is a list of ongoing projects.

- ? We recruited 99 participants for a study that will determine whether daily use of antibiotics can decrease the likelihood of COPD illness.
- ? We are finishing a two-year study of a lung growth factor that may conceivably help to regrow lung tissue.
- ? We're in the late stages of the first study of stem cell therapy for COPD patients. To date, the good news is that the stem cells don't seem to have had any bad effects...but we're still looking for signs of benefit.
- ? We're participating in several studies of new once-a-day bronchodilators that will enable more convenient and more effective COPD therapy.
- ? A study about to begin will see whether statin drugs have benefits beyond lowering cholesterol. The theory is that *all* COPD patients will have beneficial effects on both their heart and lungs from taking statins. A three-year study of 1130 patients (we will recruit 113) will examine this issue.
- ? We've taken on, with PERF's support, an attempt to find a treatment for the weight loss that COPD patients sometime experience. Early results show that a combination of an appetite stimulator and a muscle building drug are capable of increasing body weight and muscle mass.
- ? We're making progress in our long-term objective of improving the effectiveness of exercise programs used in pulmonary rehabilitation. A new way of exercising against a varying work rate shows considerable promise.
- ? We're participating in a very large study of oxygen therapy. Expanding on studies performed by Dr. Tom Petty thirty years ago, we're determining whether people with moderately low oxygen levels at rest and/or low levels of oxygen during activity benefit from long-term oxygen therapy.
- ? My favorite study, though, aims to determine the underlying genetic cause of COPD. Investigators at 22 sites around the United States are recruiting over 10,000 subjects. After 18 months work, we've recruited almost 400 subjects...well ahead of schedule. We're hoping that this study will lead to new targets for COPD therapy.

We received a boost to our spirits last month. Federal stimulus funds are being dedicated to build research facilities. We worked with our research institution, the Los Angeles Biomedical Research Institute at Harbor-UCLA Medical Center, to compose an application for a new research building to house our group and two other research groups. We've received word that our application received a high score and will likely be funded. This

building, tentatively christened the Chronic Disease Clinical Research Center, will be a 16,000 square foot, two story building. It will be a long step up from our functional but “funky” current quarters.

We ask for your support. This is our annual appeal; the only time you will be solicited. Our overhead is very low. I can assure you that your donation will be used efficiently to promote research and education in the fields of rehabilitation and COPD. We really know how to squeeze every last cent out of your dollars! All of our Board members contribute their services.

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,

A handwritten signature in black ink that reads "Richard Casaburi". The signature is fluid and cursive, with the first name "Richard" being larger and more prominent than the last name "Casaburi".

Richard Casaburi, Ph.D.,M.D.
President, Pulmonary Education and Research Foundation
Alvin Grancell/Mary Burns Chair in the Rehabilitative Sciences
Medical Director, Rehabilitation Clinical Trials Center
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