



Second Wind

NEWSLETTER

OCTOBER 2003

PERF, The Pulmonary Education and Research Foundation, is a small but vigorous non-profit foundation. We are dedicated to providing help, and general information for those with chronic respiratory disease through education, research, and information. This publication is one of the ways we do that. The Second Wind is not intended to be used for, or relied upon, as specific advice in any given case. Prior to initiating or changing any course of treatment based on the information you find here, it is essential that you consult with your physician. We hope you find this newsletter of interest and of help.

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Key Words: Flying to Europe, Rehab in Hungary, ERS, Rehab around the world, Pulmonary rehab as standard of care, tobacco epidemic, polycythema, World COPD Day, ACCP award for PERF, new email address of perf@perf2ndwind.org

Were you beginning to wonder why you haven't heard from us in so long? We have been so busy *making* news that it has been hard to find enough time to *write* about it. We warned you that we were off to Hungary and Austria for a couple of weeks. Perhaps you thought we got stuck there?
Mary Burns certainly had doubts about making it out of a few of the airports, but all is well as we catch up with accumulated work and move on to other projects.

Speaking of airports and traveling, as we struggled through long lines, security checks, broken escalators and delays requiring us to run to catch each plane, we thought of all of you. For Mary, this trip was much more difficult than the four she took right after 9/11. There was confusion and misinformation from airport personnel in the Los Angeles, Frankfurt *and* Vienna airports. If any of you have plans to fly to Europe we urge you to

carefully check and double check everything well before going. Avoid transfers, if at all possible. Be sure you have a wheelchair waiting for you, even if you don't usually need one. It will help you get through lines faster. Upgrading to business class also helps. Get to the airport at least 3 hours early for a flight overseas and try to avoid weekend travel. Oh yes, one final thought. Good luck!

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After the hassles at the airports, it was wonderful to be greeted in



Castle of Sümeg at Lake Balaton

Vienna by a smiling Dr. Janos Poszasz, our Webmaster, accompanied by other members of our group. Janos shepherded our two car caravan out of Austria, down to beautiful Lake Balaton in Hungary. We recuperated from jet lag by touring local castles, manors *and* restaurants. Tough job, but we did our best. Smoking was often the topic of conversation. To Californians unaccustomed to cigarette smoke, it sometimes seemed that everyone in Hungary was smoking. But, they were also

eating *gulyás* (*gouyaash*). We happily joined in *that* national

pastime! Did you know that *gulyás* is a soup, made with meat or fish, and not a stew?

Whatever the main ingredient, it is always

thick, delicious and spicy. If you are really brave, and want to go native, you can request that it be made extra "hot and spicy" and we guarantee you will get your wish. Add some super delicious local bread and you will have a complete meal!



Szeged Cathedral



Entrance to Deszk Hospital

The main purpose of our trip to Hungary was to visit the University in Szeged and the hospital at Deszk, on the Yugoslavian border. UCLA definitely does not look like this! Are you imagining grim, gray,

Communist era buildings? If so, you are way off. The University dates back to the 1400's and is surrounded by the charming university town of Szeged. The hospital in nearby Deszk, is one any of us would admire. It was once the country estate of a Count, and is surrounded by beautiful grounds with meandering paths, brooks, little bridges and a lake. Lovely!



Dr. Janos Porszasz lecturing

There is no way to describe the hospitality and warmth with which we were greeted. (When was the last time you had *your* hand kissed!) The physicians in our group lectured the medical staff on the latest research improving pulmonary rehabilitation techniques. Mary Burns, accompanied by a lovely physical therapist as interpreter, worked with the rehab staff and a few patients. But, oh, how she yearned to have been better able to communicate!

This new pulmonary rehabilitation program in Deszk has limited

equipment and oxygen facilities but is blessed with an enthusiastic staff eager to learn how to help their patients. Dr. Attila Somfay, who did research at Harbor-UCLA for one and one-half years, is the driving force behind this unique program. What is unique about pulmonary rehab? Lots, because except for the program of Dr. Jan Zielinski in Warsaw, Poland, it is the only one in Eastern Europe! With the guidance of Dr. Somfay, this new program is sure to become a model for Hungary, as well as for many other Eastern European states. They have some difficult problems to overcome, including the familiar ones of funding. Another serious problem is the number of patients, and staff members, still smoking. But, these problems are not insurmountable, and are similar to those we faced here in California when we first started our pulmonary rehab programs.

Besides rehab, this hospital is also



**Dr. Attila Somfay and
Dr. Richard Casaburi**

unique in Eastern Europe in that Dr. Somfay has managed to get home oxygen, and even some portable oxygen, provided for his patients. Their important asset is an enthusiastic staff willing to exchange old ideas for new ones about the importance of exercise and breathing techniques. We hope this fine group will keep in touch to let us know about their progress and their problems. We wish them well!

We all sighed with some regret as we piled into our two cars to leave Hungary for our next stop, Vienna and ERS, the European Respiratory Society conference. The hours of driving were well spent as these scientists took advantage of their time together. Current research was discussed and fine-tuned, while future projects were planned. Once in Vienna we all scattered to our various small hotels. With thirty-four countries represented by 14,000 attendees at this conference, housing was at a premium. But so was the opportunity to meet friends from other countries.

It was especially nice to see **Dr. Jan Zielinski of Warsaw, Poland**. Dr. Zielinski has been a good friend since visiting us back in 1985. He started his own pulmonary rehab program shortly after that visit, which was the first in Eastern Europe. He was honored at this meeting for his *many* outstanding contributions to the field of

pulmonary medicine and gave a superb lecture. We'll have more exciting news about Dr. Zielinski in the next newsletter.

It was wonderful seeing **Shino Sakai of Teijin**, Japan's largest



Shino Sakae in Durnstein, Austria

oxygen supplier. She was Mary Burns' interpreter during her two-week tour of Japan and has been responsible for writing some books on rehab for health care personnel in Japan. She compared notes with **Annet Rysgard of AGA of Norway** who was Mary's guide during her two visits to Norway. Our topics of conversation? Why, oxygen, pulmonary rehab, and when they would next visit California, of course!

Dr. Audhild Hjalmsen of Tromso, Norway, 500 miles above the Arctic Circle, was there also. Their pulmonary rehab program, and promotion of portable liquid

oxygen, is highly successful. They also are working to promote rehab and oxygen in the areas bordering Russia. In speaking with some physicians from other areas of Russia, it appears that this is the only section of that large country with rehab and oxygen. Heavy smoking remains a big problem in Russia as in many other countries.

Dr. Juan Antonio Mazzei of Buenos Aires, Argentina greeted us with Latin warmth and enthusiasm. We were delighted to hear that pulmonary rehab has “taken off” in that country. Mary had the honor of delivering some lectures on pulmonary rehab at a World Conference of Cardiac Rehab in Buenos Aires several years ago, when rehab in Argentina was just beginning. Dr. Mazzei is also responsible for translating our booklet on **Essentials of Pulmonary Rehabilitation** into Spanish. We hope to have an updated version on our website soon making it available for anyone to download. We still have original copies available in English as well as Spanish, but would suggest a contribution of \$2.50, if possible, to help defray costs of printing and mailing.

It was wonderful seeing these friends but even more exciting to see the successful spread of pulmonary rehabilitation around the world. The European Respiratory

Society (ERS), as well as the American Thoracic Society (ATS), have both acknowledged the importance of rehab. **GOLD**, the **Global Initiative for Obstructive Lung Disease**, also states that pulmonary rehabilitation is part of the standard of care for respiratory patients. This was considered a very controversial statement back in 1990 when Dr. Rich Casaburi, Dr. Andy Ries and Dr. Bob Chang were the first to assert this in a position paper for the California Thoracic Society (CTS). It is wonderful to see the rest of the world now also sees the value of rehab! These position papers are very helpful in getting 3rd party reimbursement for pulmonary rehab programs, so remember them if you are having problems with funding.

Just as great as the big push to promote pulmonary rehabilitation, is the effort to curb the “tobacco epidemic”. In twenty years, it is felt that tobacco use will be the greatest single cause of death in the world. Respiratory disease will become the 3rd largest cause of death, the only major disease that is increasing.

The scope of this problem was evident in seeing the many physicians from Eastern Europe who still smoke. A lovely pulmonary physician from Romania told us that she didn’t work with victims of chronic obstructive lung disease because there was nothing

she could do for them. 70% of adults still smoke she told us, including many physicians and almost all teenagers. Not only was there no pulmonary rehab, but also there was no government coverage for inhalers and most respiratory medications. She told us that many patients died of polycythemia. That is so hard to believe. Polycythemia is an excess of red blood cells, which makes the blood thick. We rarely see it anymore in the United States. It can be caused by a chronically low oxygen level in the blood stimulating the bone marrow to produce extra red blood cells. Red blood cells carry oxygen around the body. Polycythemia is the body's attempt to carry more oxygen to the body when the lungs do not work well enough to get oxygen to the blood stream. The prevention of this condition is providing oxygen. *But, there is no home oxygen in Romania.* We know that using oxygen, or your inhaler, or all the pills you have to take, can be annoying. We don't blame you for being irritated. But, the next time you are grumbling about the inconvenience, try to remember some of these poor people in other countries of the world. Perhaps it will give your day a better outlook.

There were 3,720 presentations at this meeting with 384 major scientific presentations. A lot of information is being exchanged, and

a lot of research is going on all over the world. The future is bright! Keep reading the Second Wind and we will keep trying our best to inform you about the latest developments.

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*Thanks to **Dr. Dave Lewis** of Seattle, WA for his donation to PERF and for his greetings. Dave is a pulmonologist and was Director of the Sleep Lab at Harbor-UCLA. He became a true believer in pulmonary rehab and started his own program up in Seattle. Best wishes Dave, and keep us posted on your progress. The patients down in the Torrance area still speak of you fondly!*

*Thanks and greetings also to **Elise Strauss** and her group in Anchorage, Alaska. Mary had the privilege of spending two weeks with these special folks and will never forget their hospitality or beautiful state. We send a big hug to **Rose Bailey**, who helped save portable oxygen in Anchorage. She is a very special, very gutsy lady, who is an inspiration to all who meet her.*

***Ted von Goerlitz** made a memorial donation to PERF in memory of his beloved Virginia Rose, as did Edward & Kele Thompson and Jennifer Omay.*

Memorial donations were made for Jeanne Rife's mother, Bertha

Stanford, by Jim Wood, Marge & Ralph Baxter, Donna Jeffery, Bert and Pat Ternstrom, Mary Burns, Reta Long, Rubye Richey and Susan Hesser.

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PERF would like to send special thanks to our Japanese friends at **Teijin** for their *very* generous donation. Teijin is a large Japanese company with many divisions. Their Home Healthcare division provides oxygen and other services to respiratory patients in Japan. But that is not where their efforts end. They have developed videos and teaching materials for patients. They also sponsor speakers from the United States at medical conferences for pulmonary physicians and health care personnel. PERF has been well represented. Several years ago, Mary Burns had the privilege of touring Japan for two weeks speaking about pulmonary rehabilitation. Dr. Rich Casaburi was there this August lecturing on the latest research on exercise for pulmonary patients. Dr. Tom Petty is credited with being the father of oxygen therapy in Japan, as he should also be honored in the United States.

On their latest visit a few weeks ago, our Teijin friends videoed Mary and Rich Casaburi as they sent greetings to patients at **The Japanese Respiratory Society November 14th round table**

meeting. Professor Fukuchi, President of The Japanese Respiratory Society, has organized this historic event, in which Japan joins other nations around the world in celebrating **World COPD Day**. Japan has come very far in the past few years. It is one of the few countries, besides the United States, which offers pulmonary rehabilitation and portable oxygen, as well as patient support groups, for their respiratory patients. Many difficulties are still ahead of our pulmonary patients and we must continue our persistent struggle against them. All of us, all over the world, need to join forces, support each other, and become *one* in order to overcome the devastation of this disease. **World COPD Day on November 17th** is a big first step in that direction.

The United States will also be joining this event with the first national **COPD Conference** in Arlington, Virginia, November 14-15. Check the website at www.uscopd.com for detailed information. Mary Burns and Dr. Brian Tiep will be attending and writing a report for the Second Wind.

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We are proud to share this letter, and announcement, from our PERF President, Richard Casaburi, PhD, MD.

Dear Friends,

I have received a very nice letter from the American College of Chest Physicians. Several months ago I completed an application on behalf of PERF for an award program the College supports. This Governors Community Service Award program annually makes cash awards to support worthwhile community service projects.

This year, 105 applications were received and 22 awards were made. I'm pleased to report that our application was among the successful ones. After completing a couple of forms, PERF will be awarded a check in the amount of \$5000. In the application, I stressed the educational mission of PERF. Of course, the main focus was the Second Wind and Dr. Janos Porszasz' efforts in creating our excellent website. The award carries no restrictions and will be put in the PERF general fund. There are some upgrades to our capabilities as regards our educational mission and our website needs that we will consider. We've had a fair amount of recognition for our accomplishments in research lately. It is nice to see that the excellence of our work in education is acknowledged as well. I can't tell you the pleasure I've had being associated with this organization!

Best regards.

Rich Casaburi

Receiving an award of \$5,000 is very important for such a small foundation as PERF, which operates on a shoestring. The recognition of our efforts from a prestigious organization such as the **American College of Chest Physicians (ACCP)** is just as important to us. Our request, made on the basis of value, was in competition with many far better known, funded, and professionally staffed operations. It is nice to know that the work of our *volunteer* staff is so highly regarded. Those of us putting so much time and effort into the **Pulmonary Education and Research Foundation** are honored, and inspired, to continue forward. Dr. Brian Tiep will officially receive the reward in our behalf at the next meeting of ACCP this October in Orlando, Florida. We are honored, and again thank the American College of Chest Physicians for their recognition and for this prestigious award.

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IMPORTANT:

Please note that our new email address is perf@perf2ndwind.org.

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We at PERF wish to express our sympathy, concern and condolences to all of our families, friends, colleagues and patients who suffered great losses and endured the horrific fires in Southern California.