Second Wind
NEWSLETTER

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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.

Pulmonary medicine in Sweden, European Respiratory Society Annual Meeting in Stockholm

Message from Mary: ***an update on Uppsala and the European Respiratory Society (ERS) annual meeting in Stockholm, Sweden.***

Have you thought about travel to Scandinavia but been concerned about the level of health care available? Fear not! Hospitals and health care for the pulmonary patient in Sweden, and other Nordic countries, equals that which you could expect to access anywhere in the United States. This report will focus specifically on **Uppsala, Sweden**. Uppsala is a university town of about 180,000 people, 70 km north of Stockholm. It has one of the oldest Universities in the world, teaching students since the beginning of the 1200s. (*And I used to be impressed by the ivy-covered walls of Yale!*).

City Hall (where Nobel prize is awarded)

It now has about 40,000 students studying in all the disciplines including, of course, pulmonary medicine. The buildings are a wonderful meld of the ancient and the modern, designed to educate and house those who study here. My favorite building was the circular medical amphitheater dating back before 1600. To help pay for the expense of the building, resembling a small Sistine Chapel in shape, tickets were peddled to the public for the privilege of viewing an *autopsy*. And we complain about too much gore in our entertainment! A very few "privileged" guests got a front row seat. Others had to struggle up *very* steep stairs to *very* narrow aisles, which still circle this glass-domed room. Here it is standing room only where your only support is a high, solid railing on which you can lean. We were informed that was to prevent squeamish spectators from falling down onto the autopsy table *way* below if they fainted! This architectural wonder is still used for lectures and receptions today. But not for autopsies.

Uppsala University Hospital is clean, bright and modern with a staff that understands and speaks English. Communicating is *no* problem. Walls are painted white with lots of furniture in bright, cheerful primary colors.

The pictures on the walls are also colorful and interesting, rather than the routine institutional types too often seen here. The light fixtures were ones I'd like in my own home.

Drs. Somfay and Casaburi visiting PFT and exercise lab with Dr. Boman in Uppsala Hospital Pulmonary and Exercise Physiology Laboratory.

One thing that made my eyes open wide was the staff cafeteria. Great furnishings, great food and interesting beverages. Along with the coffee, tea and coke you could also have a glass of beer with lunch. Fear not. Unlike our American brews, these are barely 1% alcohol. Sweden has *very* strict laws about driving under the influence of alcohol. A blood alcohol level of 0.002% can mean a large fine *and* the loss of a driver's license for 3 months. One glass of this light (in alcohol, not calories) beer can be safely consumed by our careful Swedish friends. Another difference in diet was flat bread and cheese severed at every meal, including breakfast and, European style, with desert.

The striking difference between Uppsala University and hospital, and one in America, was the parking

lots. There were very few cars but thousands and *thousands* of bikes. None of the students have cars. Almost everyone walks, or more likely, rides his or her bike to school or work, including senior physicians and researchers. And that, my friends, is *still* their mode of transportation even in the rain, sleet, snow and ice that you find in this city part of the year. What do you do when it rains? Wear a poncho and hood. When it gets below freezing? Remember the mittens! When it's dark? Turn on the headlights and wear reflectors. And when there is ice and snow? Put snow tires on the bicycle and ride carefully! It is not hard to believe that you are in a country populated by descendents of the hardy Vikings.

Part of one of the bike parking lots.

I was fascinated to see very elderly ladies, gray hair flying and skirts billowing in the breeze, vigorously pedaling past me. This means other changes in life style. If you ride your bike to the grocery store you can't bring home bags and bags of groceries. Besides, you bag your own groceries and no box boys are around to help you to your bike.

Do you feel self-conscious when you need to use a cane? Come to Sweden. While you don't see too many single canes, one in each hand is common. Why?
Well, to begin with, if you have an injury. it makes for better body mechanics and balance. And if you don't have a physical problem, it is a good way to keep in shape for the cross-country skiing that all Swedes do from early childhood. From 3 to 93, all age groups can be seen striding along using their poles, getting ready for the long winter season.

Margareta Emtner, Mary Burns & Dr. Bahman Chavoshan at the Yann Arthus Bertrand exhibition.

And what did I do while I was there for 3 weeks? Why, I walked along with everyone else, of course. (Prudence reigned, and I decided this was no time to enter the biking traffic.) It was a shock on my first jet-lagged day to find I had to walk 2 miles to (and back from) the University to give the first of my lectures. Especially when we had thunder, lightening and pouring rain on the way home. For a Southern Californian who hasn't seen rain in about 8 months it was true culture shock! So, what happens if you work in Stockholm, or want to spend the day there? You may be in

charge of hamburgers at McDonalds or the CEO of a large firm but you *still* pedal your bike to the train station, where you park, lock it up, and hop your train commute to work. No wonder the obesity so prevalent in the States was noticeably almost non-existent in Sweden! And I strongly suspect that the few I saw were tourists from you-know-where.

Viking burial grounds in Old Uppsala

Liquid and portable oxygen are readily available. However, it is prescribed only for patients who have an oxygen saturation below 88% or a blood gas PO2 below 55 *at rest*. Desaturating with exercise is *not* an acceptable reason for being put on oxygen in Sweden. (This is one area where we may have a disagreement with our Swedish colleagues…more research is needed in this area.) General practitioners refer patients to a pulmonologist when indicated, or when they find an FEV1 under 50% of predicted. If you are unlucky enough to have been hospitalized here in the States, you will be familiar with the one or two bed units in most hospitals for those who are not aren't critically ill. You will find a similar set up in Sweden. The difference? You are encouraged to walk to your meals in a small, pleasant dining room. A staff member will roll you there in a wheel chair, but we know that all of you would *much* rather walk, wouldn't you?

What about travel in general? Like many other countries, getting around is not especially easy for those with handicaps. Many streets and sidewalks are constructed with picturesque old bricks. Escalators seem rare, as are moving sidewalks in airports. Stairs seem more common than elevators or escalators. The contrast between cold air outdoors and the heated air of interiors can trigger runny noses and maybe even some wheezing in those of you susceptible to rapid temperature change. Also, while Swedes smoke much less than Southern Europeans, there is still more smoke than a Californian is accustomed to.

As to tolerating international air travel, be sure to get flu shots before flying. The re-circulated low humidity of air in a plane that you are stuck in for 11 or so hours makes you susceptible to catching things. I never get colds, except occasionally after an international flight. This time I got one coming and going. Of course, getting stuck for hours on the tarmac didn't help. Neither did the flight aborted by loosing an engine, flying around to empty the

fuel tanks over London (!) before landing again, and hanging around until the next day for another plane help any. These things can happen when you fly and you need to be prepared to go with the flow. Or rather, the lack of it!

Margareta Emtner & Rich Casaburi after poster session.

But it was a great trip, thanks to our Swedish colleagues, and in particular to **Margareta Emtner, PT, PhD** and her *wonderful* family. They all opened up their homes and hearts, giving generously of their time, to make our visit so special. A great big "*Tack*" to *all* of you for your wonderful hospitality.

What about the ERS conference in Stockholm? As always, part of the enjoyment of these international conferences is resuming friendships and exchanging information with our colleagues from other parts of the world. It was wonderful to again see **Dr. Attila Somfay of Hungary**, who has gotten his PhD as a result of the research he did with us at Harbor-UCLA. He joined us (Dr. Rich Casaburi, Dr. Bahman Chavoshan, Dr. Janos Porszasz and Dr. Brian Tiep) in lectures we delivered as part of a half-day symposium we presented to the Pulmonary Division at Uppsala University. We were so pleased with Attila's success in encouraging early diagnosis of pulmonary disease and in starting the first pulmonary rehabilitation program in Hungary. Rich Casaburi visited his hospital in Szeged, Hungary last week, where he presented a research lecture and was greeted with fine hospitality. Next year I hope to visit his rehabilitation unit and lovely hospital.

International friendship: Margareta Emtner (Sweden), Janos Porszasz, MD, PhD (Hungry & US) & Louis Puente-Maestu, MD, (Spain)

We also had the pleasure of touring Uppsala University with our friends **Tetsugi Watanabi and Nobu Otani of the Teijin Company** from Japan, who were accompanied by two pulmonary physicians from Japan, **Drs. Hiroshi Takahashi and Yashuro Yoshiike.** As usual, we met them often during the conference. They are committed to improving the care of pulmonary patients in Japan.

It was wonderful to again see **Dr. Audhild Hjalmarsen of Tromso, Norway**. Tromso University has a fine rehab program. It is located 600 miles above the Artic Circle, and visiting it 10 years ago was one of the exciting events in my life!

t was also good to see **Dr. Jan Zelinski** of Poland, plus too many others to mention. Why do I tell you about these people you have probably not met? Because we want to impress on all of you, the international interest and concern about pulmonary disease and rehabilitation. Emphasizing the need for pulmonary rehabilitation, and the increasingly positive attitude about COPD, is a worldwide phenomenon that you should be aware of, and pleased by. Better days are coming!

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National Respiratory Care week is from October 20-26.

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November has been designated by President Bush as National COPD Awareness Month.

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Very special thanks to **Kevin and Judy Hettich**, for their donation to the Chair in honor of Mary, who is *very* honored by this tribute.

Evelyn Gould made a donation to PERF in memory of Glenn Gould while **Barbara Borak** made one in memory of Dianna Reynolds.

Thanks to **John Boynton** for yet another donation for the Chair. Thanks also for donations made to PERF by Freda Standeford, and Edith & James Winning.

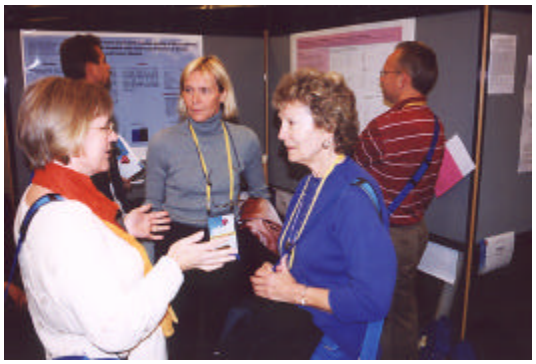
When **Dr. Brian Tiep** was asked about his impressions of the **ERS conference** he reported, "There was a lot of good information, discussion and cross-fertilization on subjects that I consider important. Examples include the early recognition of exacerbations and the use of specific antibiotics and steroids to bring rapid relief.

Also, there is some interesting, and I think fruitful, work in the area of **interstitial pulmonary fibrosis (IPF)**. They are now treating it as an active process rather than simply scar tissue. The benefit of that approach is that its inevitable progression may not be inevitable. Treatment protocols are going after an active process of inflammatory pathways. (The way I describe inflammation to my patients is a repair process gone awry, or an inappropriate repair process.) Also, lung biopsy may not be necessary in making the diagnosis of IPF. The HRCT scan and clinical history will be adequate in most cases.

There is a greater understanding of oxygen deprivation and its impact on muscles. **Cor Pulmonale** may relate to the kidneys as much as the heart and lungs."

Thanks, Brian. We hope to hear more detail on some of these subjects in future newsletters. What was my favorite session at ERS? Without a doubt, it was the presentation by **Margareta Emtner,**

PT, PhD on "*Benefits of Supplemental Oxygen in Rehabilitative Exercise Training in Non-Hypoxemic COPD Patients"*. This was the study that Margareta did as a Fulbright Scholar in her 1-½ years at the **Rehabilitation Clinical Trials Center at Harbor-UCLA**. Translated into everyday English what does this mean? It means that unlike people *without* lung damage, patients with COPD benefit from using oxygen with exercise, even if they don't "need" it, according to Medicare standards in the United States. In other words, even with vigorous exercise, their oxygen saturations stayed above 88% without supplemental oxygen.



Crowd viewing Margareta's poster, including Audhild Hjaimarsen, MD, Phd of Tromso,Norway and Mary Burns.

This study showed that giving oxygen during exercise training enabled them to exercise more vigorously and improve faster than the patients who received room air as their "placebo". Does that mean that we think that all COPD patients should be on oxygen even if they don't seem to need it according to their tests? No, we do not. What we do speculate however, is that using oxygen in exercise training during rehab would give patients a jump-start. They would be able to exercise harder and also increase their exercise tolerance.
Some of you may have had the fun of participating in this study and should feel justifiably proud of your contribution to our knowledge treatment options in COPD. It received a great deal of international interest since many countries, including Sweden, do not give oxygen even to patients who desaturate with exercise. Learning that oxygen will benefit those who do *not* desaturate, created a stir and a rethinking of attitudes. Other studies will be done to validate her results. This was an important research project and we thank all of you who participated.

Other important thoughts we took away from ERS included remarks by **Dr. Bart Celli, of Boston**. A summary of his talk said, "COPD has been associated with a nihilistic attitude. Based on current evidence, this nihilistic attitude is totally unjustified. The disease has to be viewed under a new paradigm – one that accepts COPD not only as a pulmonary disease, but also one with important measurable systemic consequences. COPD is not only preventable but also treatable. Caregivers should familiarize themselves with the multiple complementary forms of treatment

and individualize the therapy to each patient's particular situation. The future for patients with this disease in bright." And at another time he said, "The concept that COPD is a disease that progresses over time and for which there is little treatment is incorrect. COPD is a preventable and treatable disease – one where more research and the application of currently available and rational treatment can not only prolong the life of the patients afflicted with the disease but also improve the quality of their life."

"COPD is the one respiratory disease where multiple randomized trials have resulted in strong evidence of improvement in other outcomes. The administration of oxygen prolongs the survival of patients with hypoxemia and supplemental oxygen to patients with less degree of hypoxemia not only improves exercise endurance but also improves dyspnea and respiratory breathing pattern.

Pulmonary rehabilitation with exercise training has not only resulted in improvement in dyspnea, but also in quality of life, and utilization of health care resources. The evidence supporting pulmonary rehabilitation is so overwhelming, that it has become the gold standard against which new therapies such as pneumoplasty is being compared." Other speakers echoed the sentiments of Dr. Celli. Pulmonary rehab is accepted as the standard of care around the world. There is new optimism about available treatments of COPD, as well as other treatments still in the research stage.

We have given you a lot of heavy-duty information in this newsletter. What we hope you have gotten out of it is a sense of the good news about increased interest in COPD and increased optimism of medical professionals around the world. There are exciting new medications about to come on the market in the United States (some are already being used in other countries) with others still in clinical trial stage. There are new advances in oxygen therapy that we should see within the year and, best of all, an acceptance of pulmonary rehabilitation as the gold standard in the care of COPD. Watch future issues of the Second Wind for more positive news. Until then, get your flu shots, and keep exercising!

One of the parking lots at the train station in Uppsala.