Second Wind NEWSLETTER

JANUARY-FEBRUARY 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: Tromso, Norway, canes, testosterone, correct oxygen flow rates, hereditary emphysema, history of oxygen, finding less expensive prescriptions.

We hope that that your New Year got off to a better start than ours did! Have you been envying us the record-breaking heat and sunshine of Southern California? It has been great (if you are not praying for rain) but hasn't saved all of us from a nasty virus going around. The only good thing we can say about a productive cough, and all the things that go with it, is that it makes us even *more* empathetic with all of *you*. We all agree, it's no fun having respiratory problems!

Are you thinking about how cold it is where you are? Well, how would you like to be going to the pulmonary rehab program in **Tromso, Norway**? In the last newsletter, we promised to tell you more about Tromso, which is 500 miles ***above*** the Artic Circle! It has the northernmost university in the world and we'll bet their pulmonary rehab program is the most northern also! Polar night, when the sun is *never* above the horizon, lasts from November 27th until January 21st. How do you exercise when it is dark all the time? The ski slopes and the cross-country ski trails are strung with lights so it's a good guess that the streets are brightly lit also. But come summer, these Norwegians make up for almost 3 months of darkness when the midnight sun is in the sky from May 21st until July 23rd. At midnight, you can see small children playing ball, elderly ladies digging in their flower gardens and visitors like Mary

Burns gaping in astonishment. Restaurants are interesting also with traditional Norwegian foods, pizza, reindeer, seal meat and *sea gull eggs*. The latter are v*ery* fishy and *not* recommended for finicky American tastes! This picturesque town of 50,000 people is known as "The gateway to the Artic". It was the jumping off place for polar exploration so, appropriately enough, there is a wonderful Polar museum (along with 2 others) housing many fascinating exhibits. While there is a comprehensive *Same* (Lapp) collection, you might be more interested in seeing some of today's *Same* (Laplanders)

The first patient in Norway with portable liquid oxygen.

herding reindeer outside of town. If you look closely, you might even see a herder with portable oxygen! Or perhaps you will notice one of the local people using their portable oxygen to fish or even to zip around on their snowmobiles. Dr. Ulf Aasebo is the dynamic pulmonologist who started pulmonary rehab, liquid oxygen use and travel for his patients from the Tromso area about 12 years ago. Portable oxygen allows this patient to again use his snowmobile.

Dr. Aaseboe is now involved in helping the Russians to improve their care of the respiratory patient and has been instrumental in helping them start a pulmonary rehab program of their own!

Audhild Hjalmarsen, MD, PhD is the lovely lady who now directs this rehab program at the top of the world. She also does research and takes her patients on tours. Should you need any medical attention, you would be hard pressed to find a more knowledgeable or compassionate physician. We've barely touched on the wonders of this area, but want to reassure you that traveling to (one of) the ends of the world can be done while still

having access the best modern medicine available. Excuse our pun, but Tromso truly is the tops!

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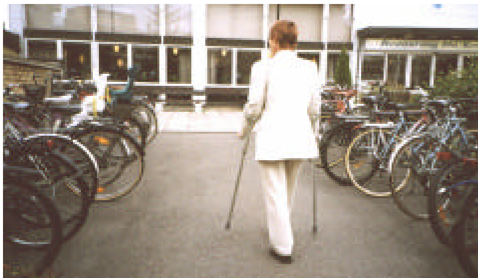
Speaking of Scandinavia, here is the picture we promised to show you of how canes are used in Sweden. Does this lady really need the cane or is she getting in shape for cross-country skiing? Actually, she is scheduled for knee surgery though you couldn't be quite sure by looking at her. Notice all the bikes outside of this restaurant, which is typical of what you see in Uppsala, Sweden.



To remind you of our philosophy to make every penny of your donations count, we ask you to look again at our updated plain brochure. It probably is the *least* glossy, *least* slick, appeal you have ever gotten! Is that because we don't care about how nice our brochure is? Not at all! If you know anything about printing costs, you'll realize we deliberately used the least expensive way possible to inform you about our purpose. Why? Because we use those funds you so generously donate for direct application, *not* on fund raising. And that segues into thanks for your generosity. In this issue, we'd like to thank *John Boynton, Jack Stevens, and Jane Martin (in memory of Shirley Van Krimpen), for their donations for the Chair.*

We also wish to gratefully acknowledge the contributions of Rubye Richey in memory of George, Mary Burns and the PEP Pioneers in memory of Ross Harrington, Hilda Swanson in memory of Albert, Georgina Benoit in memory of George, Joyce Bauman in memory of Jack, Louis Rollino in memory of Dorothy, Jo Blanche Dutcher in memory of Kenneth, and Virginia Elson in memory of David.

Thanks also to Sam & Vicky Praw, J. Melvin Fosse, The Second Wind Group, Janice Kennedy, Yasuo Masunaka, Keith & Beverly Elledge, Jean Anderson, Barbara Butler, John Mercer, Don Butler, Dyckie & H.E. Wallace, Rhoda Jean Kelley, Charles Dougherty, Bill & Cindy Wright, Bill & Shirley Grindrod, Eddy Ajkay of Bogotá, Columbia and Chris Garvey and our friends at Seaton Medical Center in Daly City, CA.

Special thanks to Dave Nelson and Jeffrey Baylock who used their matching gift programs at work to double the size of their

contributions! On behalf of all those folks out there with respiratory disease, we thank all of *you* for your generosity and your good wishes.

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In addition to the many nice notes that you sent along with your donations, we got other mail. We'll share some of these inquiries with you, since they are of general interest. (Names and places changed to protect the innocent!)

Leonard writes,

"Thank you very much for your research on COPD. My mother has COPD and uses O_2, hence my interest in COPD research. I am trying to find out what the conclusions were from:

1. Testosterone supplementation in men
2. Testosterone supplementation in women
3. research to find out what the optimum O_2 saturation should be for a patient who is on O_2 continuously (24 hrs). In other words, when we set the O_2 flow rate, what O_2 saturation should we aim for, in order to have the optimum benefits? I am told that 100% O_2 saturation should not be the aim. My question is, what would be the optimum setting?

Dr. Casaburi answered,

Dear Leonard,

I'm sorry that your mother has COPD. It is a miserable disease. I'll provide brief answers .

Testosterone supplementation in COPD (men or women) is considered experimental therapy. We used testosterone in COPD men in modest doses and found increased muscle mass and strength, and little in the way of side effects. Testosterone therapy for women is problematic in that doses we use in men will cause virilization (e.g., growing beards). We are in the middle of a 3-year study to see if a lower dose of testosterone will have beneficial effects in women with COPD.

It is generally agreed that a target oxygen saturation should be roughly in the 92-95% range. In general, when a patient ambulates, the oxygen flow rate must be increased to maintain an adequate saturation. Thus the flow rate of oxygen necessary to obtain adequate oxygen saturation should be determined at rest *and* during exercise.

Tiotropium (Spiriva) is a new drug that is available for sale in the Europe and Canada, but not in the US yet. I think it is a good drug and an advance in therapy, but not a miracle drug.

I hope this is of help.

Rich Casaburi

Sarah wrote to ask if emphysema is hereditary since her mother has

it and she is concerned about herself.

Mary responded:
There is a form of emphysema called Alpha One Antitrypsin Deficiency, which is hereditary and can be diagnosed early in life with a simple blood test. However, this is a very rare condition and perhaps accounts for only 1% to 3% of all cases of emphysema. COPD and emphysema are usually due to smoking though the susceptibility to lung damage from smoking seems to run in some families. Only 15% to 20% of people who smoke get emphysema. The question is not so much *why* do some people who smoke get COPD as why doesn't EVERYONE who smokes get it? Avoiding smoking and second hand smoke is good advice for everyone for many reasons.

Do *you* have a question about respiratory disease that has been bothering you? If so, feel free to write and ask us, either through our web site or by mail. We answer all of your letters.

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Would you like to know a little more about **the history of oxygen**? There will soon be a 3-minute segment about it on TV. Should you miss it, here is the original correspondence from **Dr. Tom Petty** to the TV producer. We quote,

"The history of oxygen is a good story. We did our first research with liquid portable oxygen back in 1965. At that time, it was a *revolutionary* idea to be able to get oxygen at all, especially outside of hospitals. *Ambulatory* oxygen was truly unique. Our original research, showing that cardiac function and reconditioning was possible, was confirmed by others including a group in Birmingham, England. They did almost exactly the same study that we did, independent of knowledge of what we had done! Now fast forward to the **Nocturnal Oxygen Therapy Trial** (NOTT), supported by the NIH (National Institute of Health), and another study done in the UK (United Kingdom) by the British Medical Research Council. They were both published in 1980 and 1981. ***Both studies showed that home oxygen improved both the length and quality of life in COPD patients with advanced disease.*** Today there are approximately 1 million people in the USA receiving home oxygen, **but not enough of these users have an *ambulatory* system**. LTOT (Long Term Oxygen Therapy) is also widely used in Japan, where we introduced it nearly 18 years ago. It is also used in Europe. But usually oxygen in

these areas comes from stationary systems. *It takes **ambulatory** oxygen to improve tissue oxygen transport to restore the structure and function of critical organs of the body.* This is why the Helios and other truly ambulatory systems are so superior to oxygen by stationary systems. Stationary systems do not allow good mobility and reconditioning.

This should really be the basis of a one-hour documentary. I would start with showing how Priestly first discovered oxygen in the late 1700s and how Dr. Alvin Barach first gave oxygen via a tent in 1922. I have skipped over many historical tidbits to get this far! And then there were the many controversies about whether or not oxygen should be given *AT ALL* to COPD patients! Our pioneering research attacked this dogma effectively, beginning with our 1965 studies. Then came the problems with reimbursement and the government cutting back on oxygen prescribing, indirectly through their curtailment of payments. The misrepresentation by oxygen suppliers did not help things. Our group organized a series of five **oxygen consensus conferences,** which had an enormous impact on oxygen prescribing and some effect on reimbursement. On and on it goes. And still, new technologies are emerging, such as a 10 lb portable oxygen concentrator, which may change the landscape. What a fascinating story, and almost no one knows it. Anyway, this is a good way to start a New Year. Thanks for listening.

Tom

And thanks to you, Tom, for this interesting history of oxygen use.

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Buying prescription medicines online may be a beneficial option for you and your family. Just make sure you know all the facts before making a purchase. For additional information, go to www.fda.gov and click on "Buying Medicines and Medical Products Online" or call 1-888-INFOFDA (1-888-463-6332).

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Whether or not you have a computer, you may be interested in the following information sent to us by **Tisha Bullock, RCP** of San Lous Rey, CA. One of her patients shared this letter from *Patty Clegg.*

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"Last July 22nd, Steve Wilson, an investigative reporter for Channel 7 News in Detroit, did a story on generic drug price gouging by pharmacies. He found in his investigation, that some of these generic drugs were marked up as much as 3,000% or more. Yes, that's not a typo, three thousand percent! Mr. Wilson did a thorough research, and checked out

all the major drugstore chains, discount chains, independent pharmacies, and even checked on some Canadian pharmacies.

So often we blame the drug companies for the high cost of drugs, and usually rightfully so. But in this case, the fault clearly lies with the pharmacies themselves. For example, if you had to buy a prescription drug, and bought the name brand, you might pay $100 for 100 pills. The pharmacist might tell you that if you get the generic equivalent, they would only cost $80, making you think you are "saving" $20. What the pharmacist is not telling you is that those 100 generic pills may have only cost him $10!

At the end of the report, one of the anchors asked Mr. Wilson whether or not there were any pharmacies that did not adhere to this practice, and he said that Costco consistently charged little over their cost for the generic drugs. They gave the link to Costco, which I will include here, so that you can go and check prices for yourself. www.costco.com, Costco Online pharmacy.

I went to the Costco site, where you can look up any drug, and get it's online price. It says that the in-store prices are consistent with the online prices. Just to give you one example from my own experience, I had to use the drug, Compazine, which helps prevent nausea in chemo patients. I used the generic equivalent, which cost $54.99 for 60 pills at CVS. I checked the price at Costco, and I could have bought 100 pills for $19.89. For 145 of my pain pills, I paid $72.57. I could have got 150 at Costco for $28.08.

While Costco is a "membership" type store, you do not have to be a member to buy your prescriptions there, since it is a federally regulated substance. If you tell them at the store entrance that you wish to use the pharmacy, they will let you in without a card."

The Second Wind had 3 of our readers check out this information. While we *cannot* verify the information from the Channel 7 TV report, our readers do tell us they have found Costco the least expensive place to get their medication. ***However*, we do urge all of you to comparison shop!** Mary checked out the price of Levoxyl 0.05 mg (or 50 mcg) and found that *her* **Heartland** (**1-800-228-3353**) mail order price was $22.95 for 90, *including* postage. Costco charged $32.09 for 100 *without* postage. **So, shop around folks, and find out for yourself what your medications cost! It pays off.**

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Hope you had a happy Valentine s Day!