



Second Wind

NEWSLETTER

November 2006

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, nor 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: Vlady Rozenbaum, Altitude Adventure, Eclipse portable concentrator, Nonin oximeter, ordering "Your Personal Oximeter" booklet, COPD Connection, oxygen at various altitudes, "Titrate when you Migrate" letter from Tom.

Have you noticed the new name added to our list of Board of Directors? Vlady Rozenbaum is well known in the pulmonary community, among professionals as well as patients. Vlady is himself an activist COPD patient on oxygen. While all of us on the PERF Board of Directors are patient advocates Vlady, and all the patients that he represents from COPD-ALERT, can help us do an even better job to understand your every day problems. But I will let Vlady

himself tell you more about who he is. We think you will agree with us that he is a valuable addition to our Board!

In his own words-----

I was born in the Soviet Union and spent the war years there. Then I lived in Poland, where I was diagnosed with bronchiectasis and underwent a lobectomy on my right lung in 1952. My condition improved markedly. I studied English and Linguistics at the Warsaw

University and later worked as editor of technical translations into English for the U.S. Department of Commerce. I married my wife, a physicist, and in 1969 we came as political refugees to the U.S. I pursued graduate studies in history and political science, ending up with a Ph.D. After teaching college in Virginia and Indiana for a while I joined the civil service. I held a variety of positions: equal opportunity specialist; Soviet/East European geographer for the Defense Department; regional expert for the U.S. Board of Geographic Names; foreign languages instructor; and intelligence analyst. In 2000 I retired on disability due to very severe COPD (diagnosed around 1980). This prompted me to get involved in patient support and advocacy activities.

I established an online group, **COPD-ALERT**, national in scope, but allowing foreign members as well. We also have as members leaders of some other support groups. We joined various COPD coalition organizations and established strong ties with the NHLBI, PERF, Alpha-1, AARC, NECA, CHASM, and the Congressional COPD Caucus. I have attended many conferences, symposia, and workshops and

spoke at the FDA hearings and on the Capitol Hill.

Membership in COPD-ALERT is free. The group has two websites on Yahoo: One is for members only (with messages, photos, links, articles, and archives) and a second is for public access



Vlady editing the COPD-Alert website

(www.copd-alert.com). The only requirement for approval is that the applicant sends me his/her full name, address, and telephone number (the address and telephone are waived for foreign applicants). I introduced this policy three years ago when we inadvertently admitted persons whose aim was to disrupt our group and harass individual members. Despite this restriction we have some 400 members and are getting new ones all the time.

Our membership forum is open 24 hours a day, seven days a week

and there is always somebody to talk to. The forum focuses on daily living with COPD including advances in COPD treatment (the latest medical and technological news from medical journals and manufacturers), information about medications and medical procedures (COPD and COPD-related - cardiovascular, GERD, anxiety/depression, smoking cessation, obesity, etc.), advocacy issues (information about pending legislation and federal regulations - CMS policies, oxygen use, reimbursements, funding for research, etc.) Members' posts describe their experiences, ask questions, and offer tips. We have notifications of patient and medical



Vlady testifying at Capitol Hill briefing on pending oxygen bill.

meetings around the country, and provide links to valuable sites. We also enlist comments from experts, some of whom are members of our group. Since a number of our members get

involved in advocacy and participate in many activities on national and local levels, our



Dr. Tom Petty and Vlady at the 6th Oxygen Consensus Conference in Denver, Colorado.

members get first-hand information from them, not just summaries from the media or medical sites. I personally have attended many conferences, symposia, and workshops and spoke at the FDA hearings and on the Capitol Hill and shared my experiences with the group. COPD-ALERT has its logo (we have a lapel pin) and a mascot, which can be seen on our website. COPD-ALERT has been featured in a number of publications and our website has links to some of them.

While I am more than busy with COPD-ALERT and COPD advocacy (hardly any time left for my doctors), my interests go beyond COPD. For many years I

have been involved in research on Russian and East European



Vlady testing the new Eclipse oxygen concentrator on a train in Poland.

history with some publications to my credit. I am on the board of directors of an international genealogical organization and of the Computer Center in my retirement community. In my "spare" time I go to pulmonary rehab three times a week and test new ambulatory oxygen systems developed for COPD patients.

(Signed) *Vlady Rozenbaum*

Everyone on the PERF Board is impressed with Vlady's COPD-Alert website and the enormous amount of work he puts into keeping it current. We are now also members of COPD-Alert and feel free to recommend it to all of you. Take a look and send us your opinion.



Memorial donations to PERF have been made by Harry & Barbara

Borak for Ross Fredrick and Jill Russell. Roy & Jo Pyle sent memorial donations for Byron Riley, while Lester & Dorothy Elbon remembered Byron B. Riley.

Earl and Jean Roberts made a memorial donation in memory of John Boynton, a loyal long time supporter of PERF and the Second Wind. We join Jean in sending condolences to his widow and many friends.

Kathleen Judge and her family sent us a memorial donation for her mother, Jeannie Judge, obtained from the proceeds of a yard sale. (What an innovative idea!) Jeanne was a long time reader of our newsletter and we will miss the notes we got from her.

Carolyn Dearen donated \$20 in memory of an unnamed good friend and classmate in her pulmonary rehab class that Mary taught many years ago. Carolyn added, "*PERF is a thundering storm of Hope for we who claim victory over COPD.*" She added that "*Exercise, Faith, Education and Fun (EFFF)*" is her prescription for *Health*. Those who remember Carolyn will be amused to learn that she is moving yet again! She

says her motto is, "*Change has always been my passport to life.*" and adds that every time she moves she makes a lot of new friends. You are amazing, Carolyn, and must have many, many friends! I'm glad you haven't forgotten those of us in Torrance.



Speaking of movers and shakers here is a vignette by our own Dr. Tom Petty

Altitude Adventure

Late last August, at the beginning of fall in Colorado, 13 oxygen patients with COPD and I boarded a bus in Denver and really got high! We actually traveled up the Mt Evans road to Echo Lake at 10,600 feet. Why? We wanted to test the functioning of a new portable oxygen concentrator, the Eclipse, at that high altitude. We wanted to experience a traveling adventure at altitudes similar to, or above those, of the cabin pressures of commercial airliners, which often are 8000 feet and even higher on occasion. We used a

continuously recording oximeter to record everyone's pulse and oxygen saturation throughout the five-hour trip. Each patient had a clipboard in order to be able to record any unpleasant feelings as we traveled to the high country. We saw some changing Aspen leaves and a few elk in an alpine meadow as we looked out at the scenery.

We then went to a restaurant situated at 7500 feet for lunch. We used our concentrators for all these activities. One person needed higher flows, so we used liquid oxygen for him. Everyone enjoyed the trip.

An analysis of the oxygen saturation reading by the oximeters showed that everyone maintained a saturation of 90% or more. In some cases the flow settings needed to be increased when reaching the highest altitude.

This was not a formal research study, but it did indicate the

performance of the new concentrator, now approved for airline travel on all the carriers that allow portable oxygen concentrators (POC) on board. Right now there are five POCs approved for this purpose.

I continue to believe that all travelers, and any oxygen patient with high activity, should titrate their oxygen *saturation*s during these activities. See "Titrate as You Migrate", on the 9th page of this Second Wind.

I also have written an illustrated booklet that explains how an oximeter works and how it can be used to monitor oxygen saturation in many activities of daily living. It is now available from Nonin, the manufacturer of the oximeter we used. It will be widely available to all oxygen patients and their families without cost. I hope you find it helpful.



Are you interested in getting a copy of Dr. Petty's booklet, "**Your Personal Oximeter: A Guide for Patients**"? Go to www.nonin.com/petty and you will be able to read the pdf file. You can also order your own copy. If you are a health care professional who would like some copies for your office or rehab program, this site will also tell you how to order them in quantity.

While there is much valuable information in the booklet we would like to reprint two of the questions we often hear.

Question: What about getting too much oxygen and retaining carbon dioxide?

Answer: This is an old myth based on misconceptions about oxygen. Oxygen itself will not eliminate or even reduce the drive to breathe. This is true even when patients retain some carbon dioxide.

Question: Can I use a higher flow rate if I am short of breath while exercising?

Answer: Yes, and it may be helpful in providing extra oxygen for your muscles as you are walking. You should return to your normal flow rate after exercise. Monitor your saturation during

both rest and exercise with your oximeter.”

Additional information on using your oximeter correctly can be found on the **PERF website** at www.perf2ndwind.org. On the home page look to the left and open **Altitude, Oxygen Levels and Oximeters** by Mary Burns, RN.



Are you frustrated because you don't have a computer or access to the Internet? We have a few suggestions and welcome additional ones from our readers.

- Give a copy of the important sites listed in this newsletter to a friend or relative with a computer and ask them to help you.
- Stop in your local library and ask the librarian for help. While they may be unable to print anything out for you the librarian can at least access a site so you can read it.
- Ask your rehab program personnel for assistance.
- Many Senior Centers have computers.
- If you still can't get help, give us a call and we will do what we can to help!



We have an additional message from Dr. Petty that we would like you to read, consider, and

discuss with your rehab programs and support groups.

I would like to make a personal request for you and PERF to join the COPD Connection. This is intended to be a loose association of all the autonomous groups that, today, are making progress in promoting COPD awareness and treatment. This "organization" will have no central office, no bylaws and no expenses. It is just a means of communicating and collectively using our clout where it will do the most good. PERF must certainly be involved in this effort.

Thanks,



PERF will of course follow the request of our President Emeritus and join the **COPD Connection**. PERF will also do everything that it can to promote this concept of working together. We already are very involved with the California Society for Pulmonary Rehabilitation (CSPR) and many other organizations. Joining an online patient network like that of COPD-Alert is another step in this direction.

We get lots of questions from our website. Here is one of general interest, especially this time of year when many of us are traveling. It is the flip side of the other questions about oxygen and altitude in this issue.

Question: Thank you for this website!! I have a question about altitude. I live in Colorado Springs, CO which is higher than Denver and Denver is 5,280 ft above sea level! I am on oxygen 24/7 @ 2 l/m. If I were to go to the California Coast to visit family is it possible that I might not need to wear oxygen?

ANSWER: Sure it's possible. But only your pulmonologist will be able to tell you for sure. First get the highest altitude at which you will be staying or visiting while in California. That probably is sea level but there are areas several thousand feet above the coast. Your doctor will want that information. He may be able to give you a yes or no answer right away, depending on your condition and blood gases, or he may want to do a HAST study. This is a simple High Altitude Simulation Test to see what your oxygen level is at a certain altitude. Usually it is done for patients going UP to altitude but I see no reason why you couldn't have one for the

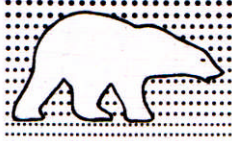
opposite reason. Medicare and insurance should pay for it, but ask in advance.

If you get the okay for going without oxygen while staying in California be sure you take into consideration the altitudes you will encounter coming and going in transit. If you are flying remember that the plane is usually pressurized to about 8,000 ft. If you are driving you will also encounter some pretty high mountain passes.

If your doctor decides that you just need oxygen while sleeping, it should be easy for you to arrange to have a concentrator delivered to where you are staying before you get there. If you have a national company such as Lincare, your regular insurance *may* take care of rental costs but ask because reimbursement policies change too fast to keep up with! You don't want any unpleasant surprises. Have a great trip, good luck and let us know how you make out.

To all of you from all of us, we hope you have a happy Turkey Day and get the big end of the wishbone! May it bring you health, happiness and easy breathing in the upcoming holiday season. ☺ ☺ ☺

**Snowdrift
Pulmonary
Conference**



**The Snowdrift
Pulmonary
Conference**

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Second Wind
Lomita, California

Dear Friends,

Titrate When You Migrate!

Titrate or titration means measuring something in increments or continuously. This is important in active patients who receive oxygen.

The availability of increasing numbers of portable and truly ambulatory, i.e., wearable oxygen devices is a major advance in the mobility and quality of life for many patients. But these new developments require some checking to see if they put out enough oxygen for all patients, under varying circumstances.

Oxygen conserving devices give a different pulse or bolus of oxygen with each breath depending on the manufacturer. These are not the same between the liquid, small compressed cylinders, and portable oxygen concentrators. Many of these put out less than one total liter a minute. Others put out more. One device or setting is not appropriate for all patients. No simple prescriptions can cover all possibilities.

Here is where titration comes in. Small, inexpensive, and accurate oximeters are available to test the results of oxygen settings and various liter flows. The settings on the conserving devices are NOT liter flows, but so-called "flow equivalents." These have been determined in a laboratory. You are the only one who can tell what your oxygenation is at what setting of your system. So learn to titrate your oxygen flows and settings to be sure your saturation is above 90% when active, as is walking or playing. Use your oximeter on airplanes and when driving in the mountains.

Ask your doctor to prescribe an oximeter for you if you are active. Most insurance companies will reimburse the approximate \$300 cost.

You will feel better and have more fun if you titrate when you migrate. Another way to put it is "measure while you pleasure!"

I'll be in touch next time.

Your friend,

Thomas L. Petty, M.D.
Professor of Medicine
University of Colorado Health Science Center
President, Snowdrift Pulmonary Conference



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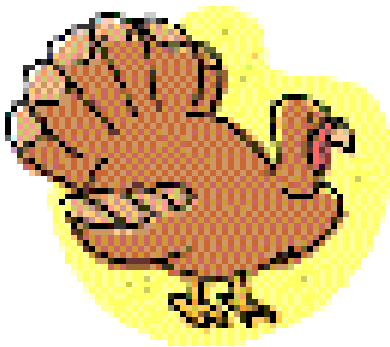
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Happy Thanksgiving!



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