Second Wind
NEWSLETTER

JULY 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.

Key words: NETT, LVRS, Altitude, HAST, breathing techniques, PLB, pulse oximetry, oximeters, COPD, Oxy-View glasses, LifeStyle concentrator

Last month we promised to give you more information about the results of the clinical trial on lung volume reduction surgery. We will start right off with a summary written by Dr. Petty.

NETT Study Results

By Dr. Tom Petty

The results of the long awaited **National Emphysema Treatment Trial (NETT) on lung volume reduction surgery (LVRS)** were recently reported at the annual meetings of the Association of Thoracic Surgeons, and the American Thoracic Society. The nationwide study was done in 17 centers. In all, 1218 patients were enrolled. All received 6-10 weeks of a pulmonary rehabilitation program designed to reach a functional optimum for each participant. 608 were randomized (i.e., by chance) to receive LVRS and to continue with pulmonary rehabilitation and medical therapy. 610 were assigned to medical therapy and further pulmonary rehabilitation. But 5.4% of these left the protocol and had LVRS while another 15 received lung transplants.

The mortality rate at 90 days was 7.9% with surgery, compared with

1.3% with medical therapy. Survival was essentially the same after two years. An earlier analysis showed that patients with very low lung had the greatest increase in exercise tolerance. Costs were far greater with surgery compared with medical therapy.

The bottom line message is that only a select group of surgical patients benefit, at high costs, and with a significant mortality risk. The presence of localized disease in the upper parts of the lungs along with function, i.e., FEV1 <20% and a diffusion test of <20% had very high mortality and should not receive LVRS. A subset of surgical patients poor exercise ability after rehabilitation are considerations for surgery. The most important part of the study was that it established pulmonary rehabilitation as the standard of care for patients with advanced COPD.

Thanks to Dr. Petty for his summary of a very long and complex study that physicians will be studying for years.

Thanks also to Chris Garvey of Seaton Medical Center for a table that summarizes the material that Dr. Petty presented to you.

Exercise capacity after PR Lung disease location in lungs	Effect of Lung Volume Reduction Surgery (LVRS)	
Low exercise capacity after PR, Disease in upper regions of lungs	Lower mortality Improved exercise capacity Improved quality of life	Benefits most
High exercise capacity after PR, Disease in upper regions of lungs	No change in mortality No benefit in exercise capacity Improved quality of life	May benefit
Low exercise capacity after PR, Disease in lower or diffuse regions of lungs	No change in mortality No benefit in exercise capacity Somewhat improved quality of life	May benefit
High exercise capacity after PR, Disease in lower or diffuse regions of lungs	Increased mortality Improved exercise capacity No significant improvement in quality of life after 2 years	Least benefit- Not suitable
FEV_1 less than 20% predicted	Withdrawn from study due to high mortality	Least benefit- Not suitable

We know that some of you will be disappointed that the results of LVRS were not more positive. Many people hoped, and expected, that this would be a major breakthrough in the treatment of emphysema for all suffers. The important finding, however, was what those of us who have worked with pulmonary rehab (and LVRS) expected: the value of pulmonary rehab. So, while you may not be a candidate for major surgery, almost all of you can be helped by pulmonary rehab. Expect to hear more about the benefits of PR in the months to come.

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*PERF would like to thank **Richard H. O'Hara & Co, Certified Public Accountants of Placentia, CA** for waiving all fees for our accounting services and for our non-profit tax returns.*

Dr. Richard Casaburi wrote the following letter to thank the **PEP Pioneers of Little Company of Mary Hospital in Torrance, California** for a donation they presented to him recently when he was their invited speaker.

" I was touched and humbled by the generosity the PEP Pioneers displayed in making a contribution to the Chair in the Rehabilitative Sciences at Harbor-UCLA Research and Education Institute. As you know, I am the current occupant of the Chair, but the Chair is structured to support <u>in perpetuity</u> the work of scientists dedicated to studying ways to improve the lives of people with chronic lung disease. PEP and I go a long way back. My first research studies in pulmonary rehabilitation would not have been possible without this group. I have always been proud of my Honorary Member status. It was a genuine pleasure to be the featured speaker at a recent PEP Pioneer meeting. I very much enjoyed the nice reception my talk on new advances in treatment of COPD received." (signed) Rich Casaburi

Kevin Hettich, Carson City, NV, made yet another generous donation to the Grancell-Burns Chair of Rehabilitative Sciences. Thank you, Kevin! **James Lynch** also made another donation to the Chair in memory of **Myrtle O. Rohko**, while **Jeanne Rife** made one in memory of **Ralph Williams**.

Altitude, Oxygen Levels and Oximetry

Summer vacations are upon us and some of you have expressed concerns about going to higher altitudes, either by flying, or by driving up to the mountains. You may remember that as you ascend in altitude the available amount of oxygen in the air decreases. That means that your arterial blood oxygen, and your oxygen saturation, also decreases. Pulmonary patients, who already have low blood oxygen at sea level, may have a problem at altitudes as low as 3,000 ft. (Remember that planes are pressurized at about 5,000 to 8,000 ft and occasionally even higher!)

Before we get started with a discussion of oxygen needs, it is important to point out that many people with lung disease, even fairly severe disease, have been evaluated and found to have no significant problem with oxygen levels in their blood. If this is true for you, great! If not, read on.

How can the doctor tell if you need to increase the liter flow of your oxygen, or if you need to be put on supplemental oxygen when you fly across the country, or drive up to the mountains? Needs vary with the individual and can be hard to estimate in the individual with lung disease.

Your doctor may refer to a nomogram, which provides an educated guess about your oxygen needs. He may order a HAST (High Altitude Simulation Test) which provides accurate information and is easily done in a pulmonary function lab. Another option is to perform a walking test to see if you desaturate, and how much, with walking. This can help him to estimate your oxygen needs at various altitudes.

Many patients, who have gone through pulmonary rehab programs and gotten sophisticated about their oxygen saturations, purchase their own oximeter. This usually requires obtaining a doctor's prescription and license number before your purchase from a medical supply company. On rare occasions, an insurance company will reimburse the purchase cost if you get a prescription. It is worth checking on.

If you wish to purchase an oximeter there are several small ones on the market. We've had the most experience with the little **Nonin 9500 Onyx finger probe oximeter**, which can be purchased for about $350.00, plus tax. But, we know other patients who have been price gouged for as much as $700.00! Shop around.

There are several places where you can now buy a small Nonin Onyx oximeter without a doctor's prescription. The Nonin 9500 is a little bigger than the size of a thimble and provides your heart rate in addition to your oxygen saturation. It comes with a long cord and can be carried around your neck like a pendant.

At the REI sports supply store they have been renamed "SportStat, and are marketed for detecting altitude sickness, also caused by low oxygen levels at altitude. Check the local store or order one at 643-382-0013 for $395.00 plus tax and shipping.

Richmark Medical Supplies sells the Nonin Onyx for $340.00 plus shipping if you live in IL, WI or IN. If you live in another state it is $359.00 plus shipping. Call 1-800-882-889 and ask for Tom.

Aeromedix sells their Nonin FlightStat (what the Onyx is called when sold without a prescription) for $367.35 including shipping. Look up their website at www.aeromedic.com

or make a toll free phone call to 1-888-362-7123 for further information.

Oximeters are great for patients who have gone through rehab and are very knowledgeable about oxygen, oxygen saturations and oximeters. Their physicians are often comfortable with having them titrate their oxygen according to their saturations. If, however, you haven't gone through rehab, or your program hasn't relied on oximetry, there are some concerns about using this technology without a thorough understanding of its limits. You should definitely get your physician's advice on this. ***Remember, oxygen is a drug, and the dose (the liter flow) should be prescribed by your doctor and changed only with your physician's advice and permission.***

We are going to provide a little crash course on oximeters, dedicated to **Iris Patton of Neff, Ohio** who asked us to tell her know more about them.

The first thing you need to remember is that the oxygen saturation provided by an oximeter does NOT have the accuracy of an arterial blood gas (ABG, a test done on blood usually taken from an artery in your wrist). However, oximeter readings are a lot less difficult (and less painful!) to obtain, are great for providing trends, and are certainly a lot less expensive.

- Several things can affect the accuracy of the reading that you get with a finger oximeter including some nail polishes, (especially blue, green, black or metallic ones), poor circulation, and having had a cigarette in the past few hours. ***If you smoke, don't waste your time and money buying an oximeter!*** The oximeter can't tell the difference between the oxygen (O_2) in your blood, and the carbon monoxide (CO), thus giving you a falsely high indication of the adequacy of the amount of oxygen circulating in your blood if you have been smoking!
- Your oximeter will give you a heart rate as well as an oxygen saturation. Don't get the two confused.
- A normal saturation, at sea level, is about 98%. Many patients with COPD will have an oximetry reading in the mid or low 90's, but that is fine. People without pulmonary disease also have low oximeter readings when they go to altitude. In Denver (5,000 ft. altitude) a normal saturation is about 90%.
- You should have an oximetry reading above 88% but don't worry if it jumps around and briefly drops below that. It can be due to your activity or circulation, a bent finger or arm, cold hands, or even due to holding your breath rather than exhaling with effort. Consistently having levels drop below 88% is of concern and should be reported to your physician.

- Most physicians prefer that you maintain an oximetry reading of at least 90%, keeping it between 90-94%. The preferred level depends on your individual condition and the type of pulmonary problem that you have. This is where you turn to your pulmonary physician for advice specific to you. Remember, each of you is an individual with different needs.
- If you are observant, you will find that pacing yourself helps keep your oxygen level up.
- You'll probably find that your oximetry readings will be high, even "normal", when you are sitting, and that they will drop with activity. If you are really smart, you will find that your breathing pattern can make a significant difference in your oximetry levels.
- Those of you with restrictive disease will find that your oxygen saturations may plummet with activity if you don't carefully pace yourself and practice good breathing techniques.

If you have COPD, when you breathe *slowly*, *breathe out longer that you breathe in*, and use pursed lip breathing (PLB) it can sometimes make the difference between a normal and an abnormal oximetry reading. **If you have a form of restrictive disease**, you may need to try different breathing techniques to see what works best for you. Slowing your breathing helps, and using PLB usually helps.

If you are doing good pursed lip breathing you should be able to increase your oxygen saturation numbers while you are doing the PLB. The lower your saturation, the easier it is to "blow those numbers up". The closer your saturation is to normal, the better your technique needs to be in order to increase your saturation numbers. There are lots of patients with low oxygen saturations who are able to increase their saturations all the way up to 93% with good PLB technique. We've seen some super stars get all the way up to 98%, much higher than the saturations they have on 2 lpm of oxygen!

WARNING! *If you work too hard at your breathing techniques, you will see that you actually lower your saturations! So, relax and don't be an over achiever!*

Why would you want to do use PLB to increase your oxygen levels when you have oxygen prescribed for this very reason? For peace of mind! If you have confidence in your ability to keep your oxygen saturations at a safe level with your own breathing techniques you never have to panic if you temporarily run out of oxygen! Also, proper breathing techniques, including a slower breathing pattern, enable you to better utilize your prescribed oxygen and you may find you need a lower liter flow. Investing in an oximeter, if only to practice breathing techniques, may be of value for those of you who have

compromised oxygen levels with activity or at altitude.

Kevin Hettich of Carson City, NV tells us that his oximeter has given him the freedom to be more active without worry. He can track his oxygen levels at various levels of activity and altitude and, *with the permission of his physician*, increase his oxygen flow to maintain his prescribed 93% saturation and so stay active even at 5,000 feet, and above, in the Carson City area.

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Andy of Monticeto, CA asks, "*What is COPD?"* COPD stands for Chronic Obstructive Pulmonary Disease. (Sometimes called COLD for chronic obstructive lung disease, and occasionally called COAD for chronic obstructive airways disease) *It is an airflow obstruction caused by diseases such as emphysema, chronic bronchitis, asthmatic bronchitis, and bronchiectasis or some combination of these problems.* This is a good question. If you are interested, we can devote more time to the description of these diseases in future editions of the Second Wind.

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The Oxy-View and the LifeStyle Oxygen Delivery Devices

Most people who use supplemental oxygen use a nasal cannula, which loops around the ears and enters the nose. But some don't like how they look when wearing a nasal cannula. Installing the tubing into eyeglasses has been used for oxygen delivery since oxygen outside the hospital was first prescribed. Older versions were clumsy, large and never became popular. The new Oxy-View glasses look like any that a patient may already be using with a prescription. They come in several versions appropriate for men or for women and your prescription can be used to replace the plain glass they come with. Dr. Petty told us that he used the Oxy-View glasses at a conference he recently attended and very few of the physicians realized that he was now on oxygen. He adds that the Oxy-View glasses are very comfortable and take the pressure off the ears.

Oxy-View also works with the Helios double lumen, but with oxygen flow going in only one nostril. Dr. Petty published an article about this in Respiratory Care back in 1973 demonstrating that this is just as effective as having the flow in two nostrils. The added advantage is that if one nostril gets irritated, you can switch the sensing flow tube of the double lumen tube to the other side.

For his personal use, Dr. Petty has just designed Oxy-Snooz eyewear. This is his name for installing J-tubes in airline eyeshades, so he doesn't have to wear glasses to bed. He is also designing something for mouth breathers when nasal prongs or the Oxy-View J-tubes won't work. We'll look forward to hearing more about this later!

Most patients wearing the Oxy-View extend their oxygen tubing down their back, though they may

also use it under their chin. There is a one-year warrantee and full 30-day money back guarantee on each purchase to return the glasses, or to exchange them for another style. Prices range up to a maximum of $249.95 for the newest half rim glasses. For more information visit the website at www.oxyview.com or call 1-877-OXYVIEW (877-699-8439).

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The LifeStyle is 9.75-pound battery powered oxygen concentrator developed by AirSep. It provides an F_IO_2 of 95% at up to the equivalent of five liters per minute. There is a rechargeable battery, which lasts about 45 minutes at a flow rate of 2 liters/minute It recharges again in two hours using AC or DC currents as well as the cigarette lighter in the car. When not being carried around, it can be continuously recharged in car, home, or office. It uses a conserver, and is sold by dealers directly to patients. Since it costs between $4,000 and $5,000 it may be a possibility for the affluent but is not yet much of an option for people on a fixed low income. One problem with this unit, besides the short battery life, is that it cannot be switched to continuous oxygen, which is a real disadvantage for many of our patients. Never the less, this technology is a real advance, and they are currently working on a battery that will last 2 hours.

AirSep says that it has passed compliance testing for a number of regulatory bodies. It is said to perform well up to and altitude of 10,000 feet.

It can be plugged into the computer terminals in the plane cabins, and can be kept on during take off and landing. It does not change the level of oxygen in the cabin of aircraft, of course.

Although portable concentrators are not yet allowed to be used during commercial air flights, AirSep tells us that they are working closely with the airlines, various organizations such as NAMDARC, AACVPR and their lobbyists, and feel they are close to getting the LifeStyle accepted for in-flight use by patients. The airlines say they are anxious to get out of the oxygen business. With all the safety testing this product has been passed, maybe we finally will have some good news for our patients who fly.

The AirSep phone number is 1-800-874-0202 and their website is www.airsep.com. We know that other companies are also working on manufacturing portable oxygen concentrators. So, keep posted for more news, and *stay well until next time.* ♥♥♥