



Second Wind

NEWSLETTER

February 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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Flying with oxygen, Alcohol, nutrition and exercise and sleep problems in COPD, Moving to a better climate or altitude for COPD, CSPR Annual Conference in San Diego

Amidst the holiday hustle and



bustle many of you joined the PERF Board of Directors in remembering departed friends and loved ones. Many of you also joined us in thinking of the future by making generous contributions

to the Pulmonary Education and Research Foundation or one of the special funds within it. Those of us volunteering for the Board know that unlike many organizations we are stingy with overhead expenses and careful about making the best use of all funds. It is *our* favorite charity and we are glad that many of you have joined us in supporting it.

Memorial donations to PERF were made by Gloria Murray, Dr. Janos Porszasz, Mary Burns and Dr. Thomas Petty made in memory of Sara Casaburi, mother of Dr. Richard Casaburi, and by Irene

Peterson in honor of her friend, Barbara, Hilbert & Patricia Ternstrom, in memory of their daughter Stacy, Mary Ellen Weger in memory of Richard Douglas, Joanne Dalby in memory of her mother Gen Schaniel, a classmate at HHSN of Mary Burns and Ann Wentink who also remembered their friend Genny Smolenski Schaniel.

Other donations were made by Ted VonGoerlitz in memory of Virginia VonGoerlitz, Dale Thompson in memory of his wife, Doris, James Lynch in memory of Mary Lynch, Hilda Swanson in memory of her husband Albert, Margaret Chaika, RRT in memory of Jack Durrance, MD, Shirley Brunmier in memory of her son Chris Tenison, Barbara White in memory of Harry Holcomb and George Richey, Stella Donatoni in memory of Jerry Donatoni, Virginia Elson in memory of David Elson, and Michael & Susan Gray in memory of Herman Gray.

Thomas Burrows made a donation in memory of Doris Burrows, Phyllis Riker in memory of Henry Smith, Carol Longo in memory of Vincent Longo, Blanche Dutcher in memory of Kenneth Dutcher, Rubye Richey in memory of George Richey, Harry & Barbara Borak for Steven Greenspan & Elizabeth

Griffith, James Lynch in memory of Dorothy Orput, Louis Rollino in memory of Dorothy Rollino, and Nancy Moore In memory of Glen Moore.

We at PERF join you in remembering these departed friends and loved ones.



Did you fly with your oxygen over the holidays?

There are increasingly more airlines allowing the use of either, or both, the Inogen One or AirSep Lifestyle portable oxygen concentrators on board. These airlines include USAirways, America West, Midwest Airlines, and Northwest Airlines. Delta, Delta Connection, Song and Delta Shuttle flights so far allow only the use of the Inogen One portable oxygen concentrators.



The Delta policy, which is typical, requires 48-hours advance notice, a note from your physician confirming the need for oxygen during flight along with the appropriate flow rate, and includes a \$25 non-refundable medical screening fee for each passenger's itinerary. United and American provide oxygen but will not, as of today, allow the use of personal concentrators. The above airlines have websites that you can look at

in addition to phoning the reservation desk.

The policies about the use of concentrators are in a state of change and in all cases you should carefully check out the *current* policy before making flight

Using your own concentrator does not end all of your travel problems and you still need to do some very careful planning before arranging your flights. This new technology is very expensive to buy, as you probably have learned. Some local oxygen suppliers, such as Lincare, have a few concentrators in stock, which they will rent to their own patients. These companies may also have some first hand advice about the problems their customers may have encountered and are another source of information to check before you start your trip. While flying with oxygen is still not an easy thing to do, breakthroughs have been made. We look forward to the future!



We greatly appreciate the donations made to PERF by
Philip Whiting, Mickee Heumann, Lillian Marineau, Jack Allen, Peggy Dupont, William Prentice, Wendell & Phyllis Smith, John Leaman, Bert & Pat

Ternstrom, Roberta Parker, E.W. Heisler, Ann McGuinness, Jewel Wolkenhauer, Dwain Essig, Dr. Thomas Petty, Dr. & Mrs. Richard Casaburi, Mary Burns, RN, Merrill Dobbs, Gerry Sandman, Carl Willoughby, RRT, Kathleen Norulak, RRT, John & Robin Leaman, Harry Hruzek, Edgar Whittemore, Charles Symens, Denise & Frank Giambalvo, Carolyn & Gary Verhage, Katie & Bill Beckley, Bonnie Steele, RN, MSN, Barbara Butler, Wesley Schull, Chris Garvey, Kris Brust, RN, Lloyd Livingstone, Joe Brandon, Linda Deighan, Mr. & Mrs. Donald Butler, Wayne & Lois Chinen, Robert Zerfing, Shirley & Philip Grindrod, William Wright, W. Kelley, Galdino & Eva Salvador, Brian & Patricia Tiep, Hugh Pierce, Edward Clair, Barbara Ueda, Sam & Vicky Praw, Kevin & Judith Hettich, John Moore, Madelyn Rowlands, and Jerry Gorby. Thanks, folks. It is the generosity of folks like you that help us continue on our mission of helping those with respiratory disease.



We Get Mail:

Many of the questions we receive, and problems we are asked about, in emails or phone calls are repeated again and again. Since these problems seem common we will combine some of these

communications and our answers to them. The letter below is a composite of several letters we have received in the past few months.

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Several emails said something like this: My husband has emphysema. I am concerned about his drinking. He has 2 or 3 shots a day. Most days he skips breakfast and sometimes even lunch, but then he starts drinking in the afternoon. He gets sleepy after he drinks, and takes a nap. If we go out for dinner he'll have more to drink. When we get home he will stay up for a little while, but then will go to sleep early. He sleeps a few hours, but then wakes up and sometimes is up the rest of the night. He doesn't do any exercise at all. Does his drinking make his COPD worse? How important is exercise and diet for some one with a lung condition? I am worried. (Signed a loving wife)

Dear Loving Wife,
We appreciate your concern. Your questions about alcohol, sleep patterns and the value of exercise and good nutrition in COPD are very important. It is impossible to cover such a large area in a letter but we will give you a few brief facts, to help you better communicate your problems to your physician.

Many physicians approve of their patients having a glass of wine with dinner at night. However larger amounts of alcohol can cause problems. A reactive depression is not uncommon in patients with COPD. Alcohol can be a form of self-medication used to provide short-term relief for these feelings of depression. Ironically, however, it may cause even more depression. Alcohol is a respiratory depressant. The alcohol may temporarily, for a very short time, relieve symptoms of shortness of breath. However, especially in someone whose breathing is already compromised, it can potentially cause serious problems. With the respiratory system already compromised by COPD, the additional respiratory depression caused by alcohol can increase the build up of carbon dioxide, the waste product of the body. This can result in sedation over and above that caused by the alcohol. Large amounts could even cause unconsciousness. In severe COPD, the body no longer adequately responds to this build up of carbon dioxide with an increased breathing rate to get rid of this waste product, which is the function of the lungs. Alcohol also interferes with the sleep pattern. While it may help someone get to sleep, it often causes wakefulness a few hours later. The amount of alcohol that can cause this rebound

effect varies with the individual. As doctors who specialize in sleep medicine can tell you, sometimes even one glass of wine with dinner can cause sleep problems for some patients with COPD. Naps during the day can prevent sound sleep at night. It also sounds like your husband is replacing food with the empty calories of alcohol. We urge you and your husband to discuss this with your physician, seriously focusing on this important problem.

It is increasingly clear that good nutrition is very important. Vitamin pills can't take the place of a balanced diet. For patients with severe COPD we sometimes recommend 5 small meals a day rather than 3 large ones, to help prevent shortness of breath after eating, which some patients come to fear. Your physician can tell you about additional specific recommendations such as the need to restrict the sodium in the diet. A multivitamin every day is usually recommended. While coffee and tea have some bronchodilator effect, their side effects can make many people nervous and interfere with sleep.

Ongoing research is making it clear that good nutrition is especially important in COPD. In most parts of the world those with COPD tend to be very thin, frail and

malnourished, which is a serious problem. When doctors from other parts of the world see American patients they find it hard to believe they are suffering from emphysema since so many of our patients are obese. Is this better than being too thin? No, it is not. Now in addition to suffering from obstructive lung disease there also may be a restrictive component caused by excess weight and a large abdomen compressing the diaphragm. Many women remember how short of breath they became in the last months of pregnancy because of a similar problem with a very different cause.

There is no longer any doubt that a regular exercise program, while good for all of us, is absolutely essential for those with COPD. It is clear that even the most limited patient can achieve dramatic improvement by gradually increasing *daily* exercise. One of the benefits of exercise is that it helps control depression. It also helps patients sleep better, as is often seen after a pulmonary rehab program. Starting an exercise program is very difficult for most people to do on their own. However, an article on our website about how to get started exercising is worth reading and may be of help. To locate this go to the PERF

website at www.perf2ndwind.org. Look in the **Education** column on the left hand side of the Home page. There is an article on “*The Importance of Proper Breathing Techniques*” that is worth reading but go on to the next page where you will find “*Starting an Exercise Program*”. If you don’t have access to a computer yourself ask a friend or relative to print this out for you.

A good pulmonary rehabilitation program can be of great help with learning how to breathe better and control shortness of breath. It is very worthwhile, not only in starting an exercise program, but also in overcoming the depression so commonly seen in patients at the beginning of rehab. The combination of exercise, better understanding of the problem of COPD, and finally being able to take charge and do something positive can make a huge difference. Learning that you are not alone, that others have the same or even worse problems, and that there is so much that can be done to live a better life makes a huge difference for the patients in rehab as well as for their families.

A newsletter can only offer general advice. To address your specific problems, we advise you to make an appointment with your physician. You may wish to make

a double appointment to allow enough time. Your physician has access to all the records and can take a history and perform a physical examination. This physician is your best source of help for specific answers. Don’t be afraid to ask questions! Be honest with your problems, since the problem that isn’t defined can’t be helped. Nothing you say will be a surprise, a shock, or something your doctor has not heard before. There *is* help available with support, medications, information and pulmonary rehabilitation. Realizing that you have a problem is the first step in solving that problem. You already are on your way. Good luck to both of you!



Donations earmarked for the Grancell/Burns Chair in the Rehabilitative Sciences *were made by Ben & Leanne Soule, Reta Long, and Louis Rollino. Thank you!*



Very special thanks to Harold Lichterman for his generous donation!



Here is another composite letter of questions we often get concerning altitude and the value of moving to a different climate.

Sharon writes, “I have COPD and bronchiectasis and am wondering

what to do. I live in Denver where the medical care is excellent. While I am not on oxygen, my lung functions are gradually getting worse. Should I move to sea level and live with my family in Hawaii to avoid using oxygen?

Dear Sharon,

This is a question that only you can answer. Many factors need to be considered, such as leaving behind a support system, friends and a neighborhood that you love. How much do you enjoy being in Hawaii when you visit? Have you ever stayed for more than a few weeks? There is no doubt that the medical care for pulmonary patients doesn't get much better than it does in Denver. However, there are also very good hospitals and pulmonologists in Hawaii depending upon where in Hawaii your son lives. He needs to check the availability of oxygen and how long it takes to get to a medical center if he lives on one of the less populated islands.

Being at sea level can make a big difference in oxygen needs, but this is something you need to discuss with your physician. It is certainly possible that even in Denver you may not need oxygen in the foreseeable future. If you have an asthmatic component, the increased mold in that moist climate can

exacerbate symptoms or even create new ones for some people. The increased humidity in itself is a problem for some, especially those with bronchiectasis, while helpful for others. Denver has a very dry climate so that will be a big change for you. Do you feel better when you visit your family in Hawaii?

Perhaps your physician can help you with some of these questions also. There are many things to consider before anyone makes such a big move. While we haven't given you a specific answer I hope we have given you some things to think about. Good luck!



The new fund for assisting and promoting visiting scientists received generous donations from Amy Walker, Alvin Grancell, Barbara & Harry Borkak. Our first visiting scientist is Janos Varga, MD of Hungary. He is already doing research with Drs. Porszasz and Casaburi in the Rehabilitation Clinical Trials Center at the Los Angeles Biomedical Institute at the Harbor-UCLA Medical Center.



The California Society of Pulmonary Rehabilitation (CSPR) is proud to announce an outstanding two day annual conference to be held in beautiful San Diego, California **May 17th-**

18th. This is just before the annual International Conference of the American Thoracic Society (ATS). This program is geared for scientists, physicians, nurses and therapists dedicated to the field of pulmonary rehabilitation. If you yourself are not a health care professional, you might like to make your pulmonologist or pulmonary rehabilitation team aware of what we consider the best program ever put together in this venue.

American speakers in order of appearance include, Drs. Bart Celli, Barry Make, Ken Landis, Dick ZuWallack, and Richard Casaburi plus Roy McCoy RRT, Brian Tiep, MD and Patrick Dunn, RRT. Well-known international speakers will come from England, Hungary, Canada and Belgium to speak at this conference. To see the full program go to the CSPR website at www.cspr.org. Why don't you download it and bring it in to your pulmonologist or rehab team so they can see for themselves what a special program this is? I'm sure they will be as impressed by the

topics and slate of speakers as they are by unusually reasonable price.

In addition to allowing interaction with these outstanding speakers, this smaller, more intimate conference is a wonderful opportunity to network with others dedicated to the pulmonary patient and pulmonary rehabilitation. We look forward to meeting many of you there!

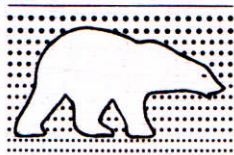


A donation in honor of Mary Burns was made to PERF by Marjorie Spitzel, while Shirley Brunmier made a donation in honor of Jeanne Rife, and William & Charlotte Zilm in honor of Dr. Tom Petty. We have been greatly honored by having you honor *us*, and we all thank you! MB



Our next quarterly issue in June will touch on the high points of what is new from the annual CSPR (California Society of Pulmonary Rehabilitation) meeting, the annual International ATS (American Thoracic Society meeting, as well as an article Dr. Petty has promised on congestive heart failure. In the meantime, stay well!

**Snowdrift
Pulmonary
Conference**



**The Snowdrift
Pulmonary
Conference**

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February 2006

Second Wind
Lomita, California

Dear Friends:

Pure Air

Most people take oxygen for granted. Some of us need additional oxygen to deal with chronic lung diseases and to remain healthy and productive. Fortunately we have modern oxygen equipment that can serve the needs of most people.

But oxygen remains under attack because of proposed reductions in reimbursement to suppliers. This can potentially limit the application of new ambulatory systems that have many advantages over the old and obsolete concentrators and e-cylinders that remain used by many. Much of the problem can be laid at the feet of the suppliers who have created an image to the government, of providing only the most rudimentary equipment with limited service, in the interests of profit. This is the result of the "modality neutral reimbursement policy," that is archaic and must be replaced. Hopefully public pressure by the over 1 million users and the physicians who prescribe oxygen, can be used to gain legislation that will support use of the most useful and rehabilitative methods of oxygen administration. Ambulatory oxygen helps improve survival and reduces hospitalizations, compared with stationary oxygen. Thus it is cost effective.

Oxygen was discovered by Joseph Priestly in 1774. He produced it from chemicals that can be caused to release oxygen. He captured this "Pure Air," as he called it, in an inverted glass cylinder placed over water to catch the bubbles of oxygen that came from the chemicals. He and two mice breathed this "pure air," and Priestley noted a "light and easy feeling." "Who can tell, but in time this pure air may become a fashionable article in luxury!"

Oxygen is not a luxury, but a necessity to be able to live and enjoy life in the modern era. Congress, it is time to act!

I'll be in touch next month.

Your friend,

Thomas L. Petty, M.D.
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