



Second Wind

NEWSLETTER

FEBRUARY 2001

PERF, The Pulmonary Education and Research Foundation, is a small but vigorous non-profit foundation. We are dedicated to providing help for those with chronic respiratory disease through education, research, and information. We hope this newsletter is worthy of our efforts.

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Is it too late to wish all of you a belated Valentine's Day? We really were thinking of you on the 14th, and would like to add our love to all the other messages we hope you received.

And as usual, we have been receiving messages from all over the United States, as well as from our friends in Japan. Turkey and places like a Kibbutz in the Jordan Valley on the shores of the Sea of Galilee. Doesn't that sound exotic? Along with fascinating details about the Kibbutz we are warned, however, that it is a horrible climate, 200 m below sea level. But the true message, for all of us, from this correspondence, is that pulmonary disease is blind when it comes to nationality, sex, religious beliefs or economic background. It is only by working *together* and *ignoring* the boundaries of borders, and other artificial ways we separate each other, that we will eventually overcome this devastating problem.

Most pulmonary rehabilitation programs in Southern California have already embraced this truth. At a recent meeting of the California Society of Pulmonary Rehabilitation, the first planning session of the upcoming **Respiratory Rally for Research** was held with representatives of many of the programs. Enthusiasm is already running high among staff and patients about this very special Rally to raise funds for the first Chair dedicated to pulmonary rehabilitation research. Why? Well, we all

look forward to the education, and interaction between patients, clinical professionals, scientists and industry. We also happily anticipate all the *fun* we'll have at this best Rally ever. But most of all, it will be a wonderful opportunity to join together in our fight against respiratory disease. Education and research are the two big guns needed. The activation of the Chair, and the increased science and education this will produce, is one way all of us can help.

You have read Dr. Petty's letter. We already have several representatives of industry committed to this goal. Dr. Petty and Mary Burns have pledged their support as well as the family of Robert Allen McDonald, whose name will be added to the cause in memoriam. The campaign is off and running before even being officially started!

The names of all contributors to this 500 club will be inscribed on a plaque to be hung in the Rehabilitation Center. They also will receive a certificate of participation suitable for framing, if they so wish.

The Respiratory Rally for Research will be held at Long Beach Memorial Hospital on June 22nd. Speakers will include Dr. Tom Petty, Dr. Rich Casaburi, Dr. Paul Selecky and Dr. Brian Tiep, all as famous as stand-up comedians as they are for their legitimate science! Watch for more details in future newsletters. Seating will be limited to 325 so early reservations will be a must. Start thinking *now* about how you too can join us for this once in a lifetime Rally!

Dr. Dave Lewis of Seattle made a donation in honor of Mary Burns as did Kevin Hettich of Carson City. Both donations are dedicated to the Chair with sincere thanks from Mary for the honor they do her.

With all the recent publicity about rolling blackouts and stage 3 alerts in the paper many of our patients on oxygen concentrators have expressed concern, and even fear, about the effect this might have on them. There have been stories exaggerated by the newspapers suggesting that patients head for the nearest fire station or hospital in the event of a black out. *Not necessary!* **This is the time to stay calm and remember your pursed lips breathing!** Any of you, unless you are on a ventilator and totally unable to breathe, can get by for *much* longer than an hour without oxygen. Please remember that

these blackouts are scheduled only during the day and only for one hour at a time. *Everyone* is angry about the potential inconvenience of rolling blackouts as well as the increased cost of electricity. But please be assured that this should *not* present the potential physical danger of *extended* blackouts, such as those caused by earthquakes and other disasters.

Ventilator patients, by law, always have stand by emergency equipment for the event of a power failure. These families should also notify local police and fire departments that they are on a ventilator. It is not considered necessary for those only on oxygen concentrators

We also assume that all of you on concentrators know that by contacting your local electrical company you will get a financial reduction of your costs. This is true for all electrically driven medical equipment including nebulizers and electrical beds. If you live in a hot climate and your doctor feels you need air conditioning even that may be eligible for a refund. If you have not done so already, call today and request information about the Medical Baseline form. This may have a different name in different parts of the country, but all electrical companies should have a similar program.

Please read the following article by **Craig Murga, Center Manager of Lincare, Torrance, CA.** who will address this problem in greater detail.

With the ongoing problem of rolling blackouts in California, we have seen increased concern about the possibility of losing power for one hour. This has raised such concern that some patients have gone to the extreme measure of purchasing gas-powered generators to alleviate their anxiety. In many parts of the country it is an annual event to experience long-term power interruptions because of blizzards, hurricanes, tornados, electrical storms, or flooding. The possibility of rolling blackouts should be no more than minor inconvenience but this gives us the opportunity to discuss emergency preparedness for more serious events. **All of us should take a few moments out our busy schedules to prepare for a natural disaster.**

The first thing I would like to discuss is using gas-powered generators to run concentrator systems. Most generators are wonderful when it comes to running a light bulb. But, **because of the low output on most generators, typically they are insufficient to run a concentrator. Also, generators tend to constantly cycle, causing concentrators to blow fuses. So, if you're going to use a generator to run a concentrator, make sure it**

works, and find out where the reset button is located on the concentrator.

Then there's the problem of **storing gasoline** for the generator. How much gas do you store? Can you store it in a safe location away from any heat source? How often do you rotate your supply? Gasoline *does* go bad!

You should also consider an alternative location if you need to relocate during a disaster. Notify your oxygen supplier *in advance* of the alternative location so that they can find you if the occasion arises.

All oxygen suppliers should have a disaster plan policy in place to prepare for the inevitable. If you are unaware of your company's policy ask them to send you a *written* copy.

If you have a concentrator you can help yourself by always maintaining a sufficient stock of cylinder gas to see you through an extended power failure. If you use 2 LPM, three cylinders will give you about 18 hours of oxygen. **By reducing the oxygen flow to 1 LPM you will get approx. 25 hours of oxygen usage. Remember, most oxygen users can go without oxygen for extended periods of time without suffering any debilitating effects.**

Take a few moments to prepare a disaster kit to be kept in a safe area.

1. Include a particle mask if you are prone to bronchospasms from dust.
2. Have an extra inhaler and medications in the kit. **When you store medications be aware of the expiration dates on your meds since you will need to rotate them on a regular basis.**
3. You should also have a portable radio with long life batteries stored separately to help you find relocation centers if necessary. A radio also helps you connect with the rest of your community, which reduces the level of stress one of the most important things you can do for yourself.
4. Don't forget a few bottles of water and some easy to store food.

When the Whittier Narrows earthquake hit I was a new, unprepared manager responsible for 1500 patients on oxygen or life support systems. And let me tell you, I was not the calm one of my staff, but it did prepare me professionally for the future. It was the Loma Prieta earthquake that made an impression on me to become *personally* prepared by getting my disaster

kit in place. So, when the Northridge earthquake hit, 3 miles away from my home, we were the only ones in our complex prepared at 4:30 am that morning. That morning we went downstairs and opened up the kit. We got out the battery lanterns, turned on the portable radio, fired up a pot of coffee from the propane stove, and made several new friends as others started to gather, drinking coffee and hot chocolate at my home. **If you haven't yet prepared do it now!**

You can find more information on disaster preparedness by checking the front pages of your phone book, contacting your city hall, or checking with your local chapter of the American Red Cross. You can also find some excellent information on the web at; www.fema.gov/pte/prep.htm

Thanks, Craig! That was great information and a great reminder for all of us. If you would like to contact Craig he can be reached by writing **Craig Murga, Center Manger, Lincare Inc. 2230 Amapola Ct., Torrance, CA 90503. His phone number is 1-800-251-7322.**

Donations were made to PERF in memory of Robert Allen McDonald by Lisa Risley, Jane Garfield, Christine Chigas, Ray & Theres Kubiak, John & Kathy Biesiada, Charles & Patrica Brothers, Mr. & Mrs. Wm. Sousounis, Pat Helfrich and Wm. Giannopoulos. Virginia Elson made a donation in memory of David Elson, Lois Skidmore in memory of Jack Bauman and Hilda Swanson in memory of her husband, Albert. Please accept our deepest sympathies.

Do you need some good books on pulmonary problems for your library? There are 3 that we would like to highly recommend to you today.

1. The 3rd edition of **ENJOYING LIFE WITH COPD** written by **Dr. Tom Petty and Lousie Nett.** is a 200 page booklet yours for only \$10 including shipping. Call 1 (303) 839-6755 or e-mail lberteau@aol.com. Checks should be made payable to Thomas L. Petty, MD and mailed to 1850 High St., Denver, CO 80218.
2. Better Breathers TRAVELER, written by the ALA of San Diego and Imperial Counties is 55 pages of great travel information. Telephone (619) 297-3901, e-mail Kathy@lungsandiego.org or send a \$12 check to ALA of San Diego a & Imperial Counties, 2750 4th Ave, San Diego, CA 92103.
3. **The 2001 edition of Breath' Easy**, compiled by Jerry Gorby, is hot off the press with a listing of places all around the world where you can

obtain oxygen. This is a wonderful companion to the Better Breathers TRAVELER and a must for reference libraries in rehab programs. Call toll-free at 888-699-4360 or e-mail gorby@mymialstation.com for further information.

Do you remember that last month we had an article by Craig Murga about oxygen from concentrators vs. liquid? We didn't have room to finish it. As promised, here is the second part of Craig's article. Refer to the January newsletter for part 1.

Another problem that can occur with different types of oxygen delivery devices is a condition of *perception*. For those who use supplemental oxygen the only sensory organ we have is the *nose*. Over time the *flow of oxygen passing through the nose* is a conditional response that equates the feeling of *airflow* with the feeling of *well being*. In other words, when you're short of breath, the oxygen provides you with relief.

This phenomenon was well understood years ago when we had concentrators that would fail very quickly. Concentrators checks would turn up all the time with purity reading of 21%, the same as room air! Back then, the frequency of servicing these units was every 4-6 weeks to try and catch this problem. But what we *always* found was that the person using the oxygen was totally unaware they were not receiving any oxygen.

We can also see this conditioned response happen with an oxygen delivery device called the enricher system. These units only put out 40% purity, but *deliver* a flow at *twice* the liter flow of a concentrator. We would see patients who used enricher units and also used cylinder gas adjusting the flow to match the other unit. This conditioned response can really throw oxygen users for a loop when they try out, or switch from, concentrators, liquid systems, or cylinder gas.

Concentrators have a working pressure of 20 psi, as do some liquid oxygen systems. Other liquid oxygen systems work at 50 psi like cylinder gas. So, using different types of delivery devices can cause a very real problem with perception. To help those using oxygen better understand this cause and effect relationship, I typically will try to explain it in this crude fashion. **If you turn on a garden hose with a spray nozzle at the end it would appear the flow is much greater than without the nozzle. But, if you place one hose with a nozzle over a bucket, and another hose without a nozzle over a different bucket both, would fill up the buckets at the same rate. The only thing that changed in the process was the pressure, not the liter flow.** The problem of perception many time leaves

the oxygen user feeling as if they're getting better oxygen from one device than from other devices. But **the reality of this is that the body's level of oxygen saturation is dependent on inspired gas not perception.** Many times just knowing how this works helps someone to overcome how they feel with different oxygen delivery devices.

Thanks again, Craig! Hope that answers some of the questions that we have been getting.