



JANUARY 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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New Year's Resolutions. Did you make any? Have you kept any that you made? If we took a survey, there is no doubt that high on everyone's list would be "**EXERCISE MORE**". One person who has managed to increase his exercise capacity *dramatically* since the first of the year is a regular correspondent, **Ron Peterson**. How did Ron do it? Well, he had a little outside help. In fact, he had a *lot* of it. Ron started the New Year with a *new lung*. Ron sent frequent reports on what he was doing to maintain his exercise, but we never heard any complaints despite the fact that his pulmonary function tests showed his FEV1 was only 10% of predicted. You don't have to be a pulmonologist to figure out that's not very good. Since his lung transplant he is back up to 45% of predicted and he can again talk and walk at the same time. Knowing Ron that's pretty important! He used to start his meals with the desert. Why? Because he would be too short of breath to eat cake if he ate potatoes first! Ron's first day after surgery he was walked every 6 hours but got evicted from ICU because he kept hounding the staff to walk him more. That's our Ron!

We could go on for pages, but if you want to read more, go to <http://www.geocities.com/HotSprings/Spa/7154/index.html>. Click on Post Lung Transplant info and that should get you to Ron's web site.

Memorial donations have been received from Toni Groveman in memory of her mother Jeanette Hamblin, Georgia Cline in memory of Andy, Gena Benoit in memory of George, and Jo Dutcher in memory of Kenneth

Who said a nurse is with out honor in her own home town? Mary Burns was deeply touched to receive the following letter and donation for the Chair.

My Pulmonary support Group at Hospital for Special Care in New Britain, Connecticut (Mary Burns' hometown!) recently held its annual holiday celebration. The group had previously decided that they wished this year's freewill collection to be donated to the Alvin Grancell/Mary Burns Pulmonary Rehabilitation Chair. I have known Mary throughout the years and her encouragement and support have been invaluable in the expansion of my facility's Pulmonary Rehabilitation Continuum of Care. She even "squeezed" in a visit to my hospital during a recent trip back East. Dr. Casaburi's work has caused us to rethink our views on exercise training in people with severe lung disease. We now offer a three-times-a-week exercise program (\$1 cost per week to participants) and have seen a very significant increase in strength, endurance and quality of life (as well as decreased hospitalization days) in our 2 ½ year history. These individuals (with fev_{1s} of 9-29% of predicted!) now do 15-35 minutes on the treadmill, 15-30 minutes on a stationary bike, and stretching and toning exercises! Thanks Mary and Dr. Casaburi! My group also salutes Mr. Grancell for his vision and backing of this much-needed project.

Please accept our donation of \$500.00 towards this worthy cause.

Sincerely,

*Janet B. Bowen, BA CRT
Pulmonary Rehabilitation Continuum of Care Coordinator/Pulmonary Medicine
Research Facilitator*

Our thanks to YOU, Janet, AND to your wonderful group. We appreciate your donation, and even more we appreciate your support Thank you from all of us, especially Mary, for joining in our crusade to help those with pulmonary disease.

Other donations for the Chair have been received from from George and Rubye Richey, as well as Gisela Ventura. Thank you!

Mary Burns and the PEP Pioneers have made donations in memory of **Elizabeth Connolly and Jack Bauman**. We don't usually write eulogies since so *many* of the friends we loose are special, and worth writing about. Their stories and accomplishments could take up the whole newsletter. Elizabeth and Jack, however, were two people that we knew well, and that many of you also knew, having seen them on the PERF video, or on slide presentations Mary has shown around the world. Both of them were an inspiration to others, as well as to the health care professionals fortunate enough to work with them.

Elizabeth had the distinction of walking a 10 K several months after graduating from rehab! She got a medal even though, of course, she was the oldest person in the race! She was also the only "racer" on oxygen at night. What a marvelous accomplishment. Elizabeth was also proud to have served as the patient representative on the PERF Board of Directors, as well as having once been the secretary.

Jack wrote many articles for the Second Wind and many of you read about how he managed to travel with oxygen, and about his experiences with transtracheal oxygen. He also helped Mary put together a series of slides for her tour of Japan, which helped inspire our Japanese friends to start their own pulmonary rehab programs. .

We join with all the families and friends of Elizabeth and Jack in mourning our loss. But we also wish to celebrate and honor the remarkable achievements in their lives. They both handled their severe respiratory problems with courage, humor, and the remarkable ability to turn that disability into a force for good that spread around the world. Elizabeth and Jack, we miss you, we salute you, and we will remember you always.

*Ann Wentink and Dr. Ralph Richardson made donations in honor of Mary Burns.
Thank you, my friends.*

Copied from the CMA Alert, 12/14/00

Medicare Patients to Get Drugs For Less

We don't usually tell you local news, but this is too good not to mention. CTS, The California Thoracic Society, has told members that California patients enrolled in Medicare can now buy prescription drugs at the Medi-Cal rate, plus a 15-cent processing fee for each prescription. This is potentially-a major savings over retail prices. The reduced price is available at all California pharmacies that accept

Medi-Cal. Gov. Davis in 1999 signed into law SB 393 (Speier, D-Hillsborough), a bill to make prescription drugs more affordable to Medicare patients. The lower rates are available to seniors over age 65, and those under age 65 who are disabled and have a Medicare card. There are no forms to fill out, and patients' Medicare cards are proof of eligibility. We hope that this program will soon spread to other states! For more on the program, check this web site.

<http://www.cmanet.org/publicdoc.cfm/402/207/GENER/563>

A very exceptional gift for the Chair has been made by John and Alice Moore . Please accept the thanks of all of us!

As of December The Health Care financing Administration (HCFA), which oversees Medicare, announced that it would begin paying for **PET scans** used to diagnose cancer of the lung, esophagus, colon, rectum, mouth, and throat cancers and lymphoma and melanoma. Previously Medicare paid for PET scan studies in very few instances. The HCFA announcement will give physicians greater latitude to order PET scans for Medicare beneficiaries suspected of having lung and other cancers. It is expected that Medicare will implement its new PET scan policy no later than July 2001.

Our grateful thanks to Alan Morrison, Weldon Kelly, Donald Butler, Yasuo Masumaka, and Dr. & Mrs. Paul Selecky for their generous donations.

We've gotten a lot of positive response to sharing a little of our e-mail with you so here are some more questions that may be of general interest.

An occupational therapy student asks, "I was discussing the importance of exhaling during a concentric or isometric movement with a peer of mine. It was my understanding that holding your breath during this type of movement could be damaging to brain cells, but I am not for sure. Is this true and if so, could you explain or direct me to a resource that gives me the scientific reasons for this type of breathing?"

We turned this one over to Dr. Brian Tiep who answered:

The question of breathing technique during exercises such as weight lifting and isometrics leads to many strong arguments for or against *any* technique. Yet, there is little definitive research to answer these questions and bring conclusive scientific support for any of these techniques. The most outstanding exception to this notion is pursed lips breathing. There is considerable evidence that good pursed lips

breathing (PLB) will relieve breathlessness and improve the body's ability to gather oxygen. Patients with COPD especially appreciate these benefits.

However, breathing is more than the exchange of gases: oxygen in, carbon dioxide out, repeat as necessary. Breathing engenders a personal philosophy and character that is highly individualized. To be sure, people's breathing patterns are, in part, a response to the physiological needs of their body. They are also a reflection of their emotions, their creative juices, and their ability to manage the situation at hand. There is no one breathing pattern that fits all.

Control of breathing is enabling. It establishes a rhythm, in singing, playing wind instruments, stretching, thinking and creating a character inherent to a chosen endeavor. Indeed, breathing is essential to all bodily processes as it creates a balance and a confidence when we can consciously bring it under our control. It is visible, modifiable and therefore such control often engenders a sense of empowerment.

When applied to exercise programs, breathing techniques often produce a rhythm that takes the exercise to fruition. The pattern that is created is highly individualized, but is usually smooth and flowing, so that the exercise itself flows. Hence, very little breath holding is involved. And, when it is, it is usually transient; perhaps 1 or 2 seconds. The problem with breath holding is that many people bear down create a pressure inside their chest, similar to bearing down to have a bowel movement (technically known as a Val Salva Maneuver). This bearing down pressure inside the chest can be felt by the heart and major blood vessels. In persons with a normal heart and lungs, the impact is minimal because it is rapidly compensated by the body.

You were concerned that breath holding may damage brain cells. This is very unlikely. Breath holding is also unnecessary. During any exercise you would be much better served by a smooth and flowing breathing pattern. This would apply to both weight lifting and isometrics. A long slow exhalation during isometrics will prevent the build up of pressures and help to comfortably maintain the effort a little longer.

Enjoy your exercise and the New Year,
Brian L Tiep, MD

Whew! That was some explanation, Brian! Thanks for your information.

This is from Alvin Grancell, **My prayer for today.....**

God, grant me the Senility
To forget the people I never liked anyway,
The good fortune
To run into the ones I do,
And the eyesight
To tell the difference.

Thanks, Alvin. That's our prayer, too!

Did you know that a recent Dartmouth study shows that 87% of popular movies contain tobacco use? Before the ban only 1% of actors used a name brand product in films. That is now up to 11%. Movies are beginning to look like cigarette ads.

More mail,

John writes, "Will moving from sea level to 1,400 feet make my breathing worse? The air seems much better up there. If the altitude does bother me will I adjust with time?" Good question, John, and one we hear often. The first thing you should do is ask the opinion of your pulmonologist who knows your general condition. There are many things that need to be taken into consideration, such as the oxygen level of your blood. In any case, before putting yourself through a move, it would be wise to spend several weeks or a month in that area to see how you feel in general. It takes about one week to adjust to altitude. However, those with respiratory problems may find that they feel better moving to a *lower* elevation rather than a *higher* one. You probably will hear that an altitude of 1,400 feet is not significant but, on a practical level, I've had several patients tell me that they were uncomfortable when they moved. Everyone is unique. Your oxygen saturations at altitude are what are of concern. You will want to make sure that you stay above 90% (or higher if your doctor so recommends) even with exercise. This may require putting you on supplemental oxygen.

Speaking of oxygen, we received a phone call from someone who felt that liquid oxygen was superior to oxygen that comes from a concentrator. He had some studies that showed higher saturations in patients who were on liquid, vs. the saturations of those on a concentrator. That is very interesting, and we are glad that this subject was brought up again. We really don't doubt their results. As you know, when people are active, we feel very strongly that they should be on a light weight portable system, such as liquid. *But, there is no difference in the oxygen*

delivered to you by a concentrator, by compressed gas or by liquid. What may cause a problem is the **inaccuracy of the liter flow**. Concentrators in particular should be checked on a regular basis. Most manufacturers recommend a check every 3 months to make sure that when you have set the flow to 2 liters per minute you are *getting* 2 liters per minute! Your oxygen supplier should have a flow meter which can check the accuracy of liter flow of *any* of your equipment. It is worth doing periodically since we have occasionally found flows that are seriously inaccurate.

Message from Mary

I've recently received many questions about the history of the **Respiratory Rally** and the early days of pulmonary rehab, since not many of us in practice date back to that time.

More than 20 years ago, when my first patient support group was being formed, I was very fortunate to have a pulmonary rehab graduate named **John Eels**. Back in 1978 John helped to organize this first group, which called itself the PEP Pioneers. PEP was the acronym for Pulmonary Education Program, and Pioneers was chosen because this was one of the first such support groups. They were true pioneers in a new area.. John was a recovering alcoholic who had formed a successful local AA chapter. He felt strongly that they should instill some of the AA principles into a self-help group for pulmonary patients. These Pioneers decided that it was important to keep in touch with each other, to express concern for one another's health and progress, and to continue learning about their respiratory problems. It was a warm, loving and supportive environment stressing the positive, and discouraging critical, negative comments and attitudes about each other. They all became very special friends whom I will never forget. They taught me much of what I know, and were fiercely supportive. **Mary Mugford**, another patient who, along with John, was a strong leader, used to remind everyone that "Laughter is internal jogging". It was their motto, and there was a lot of internal jogging that went on! The group was a success but John, their leader, was depressed. It wasn't enough. There should be *more*.

Sitting on his hospital bed (which was most unprofessional in those days) I desperately brainstormed ideas to pique his interest and penetrate his depression. Thus was born the idea of a Respiratory Rally. The plan was grandiose. We would invite all the patients, family members and medical staff of pulmonary rehab programs in Southern California to join together for a day of fun and education. *The purpose was to show everyone that they were not alone, nor even limited to one small hospital group.* Those with respiratory disease, and all those who cared for them, were part of a larger family who, when gathering together, could

celebrate this positive connection in their lives. We worked together on weekends and many evenings, struggling, brainstorming, to get this new idea up and running. Was it worth the effort? Yes!

The first Respiratory Rally in October of 1981 was a huge success. Dr. Ken Moser of UCSD, an internationally renowned physician, was our first key note physician, thus establishing a tradition for excellence in speakers lived up to by most subsequent rallies. Dr. Brian Tiep and Dr. Paul Selecky were there, at the first Rally and at every Rally since. Faithful friends! The Rally become an annual event, attracting over 300 people each year. We were *honored* to have the idea copied in other parts of the country, and the world, including a Rally held in a castle in Belgium! The Pioneers were delighted. Our goal was to reach out to others, share information, and become one group in purpose. We succeeded.

With that concept in mind, at that first Rally, the coordinators of the Pulmonary Rehab programs also met. Those many years ago, they were all nurses, and so they called themselves the **Pulmonary Nurses of Southern California**. Most of us worked alone in our hospital setting. *Now* we had friends with similar problems to whom we could turn to for advice, support, and sharing of information. Many hospitals at that time wished to keep information about this new type of service private, to themselves, and definitely not given to “competitors”, especially if their program was successful. But we quietly did what was right for our patients, and for the advancement of pulmonary rehabilitation. We shared information, friendship and support.

As the years passed, and many respiratory therapists entered the field of pulmonary rehab, the Pulmonary Nurse group disbanded and merged into **CSPR, the California Society for Pulmonary Rehabilitation**. The goal of CSPR was and still is to support and help each other, to help our patients, to learn better methods of education, to promote research, as well as to help each other with financial problems now caused by HMO’s and Medicare

Also in keeping with this philosophy, the **Pulmonary Education and Research Foundation (PERF)** was formed to support education and research, but *also* to reach out *beyond* one hospital, or one region, across the country and across the seas. *Every* patient with pulmonary disease should now know that he or she is not alone, not just a member of a small group, or even of a regional group. Each person with pulmonary disease, no matter where they are, should know that they are part of a *world wide community that shares common problems, concerns and commitments to improving their lives and health, no matter what language is*

spoken or where they live. It is only by all of us joining forces in this common cause that we will succeed.

PERF may have a finite existence, but the **Alvin Grancell-Mary Burns Chair of Rehabilitative Sciences**, the next step in this continuum, is here in perpetuity, to continue forever, working to improve the science of pulmonary rehabilitation, the education of those who practice it, and the improvement of those who are afflicted.

There fore, it seemed most appropriate when Dr. Tom Petty suggested a **Rally for Research** to help fund the Chair. He offered to be a keynote speaker, and is enthusiastic about again participating and “making this the best Rally ever”. Dr. Petty spoke at the first of many Rallies back in 1985, yielding to the many invitations of Mary Mugford. It is now also appropriate that all these groups with mutual interests, should again join together for yet another day of fun, education, friendship, *and* support for the *future* of pulmonary education and research.. This big day will be **June 22nd** at Long Beach Memorial Medical Center. Mark it on your calendars *now!* We’ll give you more details later on how you *too* can be part of what promises to be a *very* special event.

From Ann Wentink, a timely article about infections, the very best kind.

Smiling is infectious; you catch it like the flu,
When someone smiled at me today, I started smiling too.
I passed round the corner and someone saw my grin.
When he smiled I realized I’d passed it on to him.
I thought about that smile, then I realized its worth,
A single smile, just like mine, could travel round the earth.
So, if you feel a smile begin, don’t leave it undetected.
Let’s start the epidemic quick, and get the world infected!