



JULY-AUGUST

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.

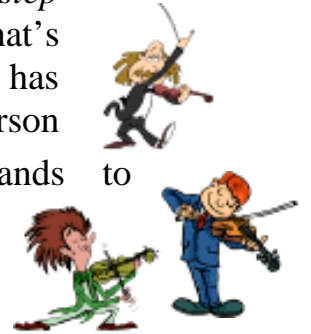
It's summer time and the living is lazy. So is your editor! It was really hard to stay hunched over the keyboard during this warm weather but here, finally, is the newsletter.

The big news, of course, is the smashing success achieved by the *Rally for Research*. About 330 enthusiastic participants gathered for a spectacular day of entertainment and education. You missed something special if you weren't able to join us. The team at **Long Beach Memorial** deserves a huge hand for hosting the event, and for doing such a great job in organizing the details! Everything went smoothly in spite of the huge crowd. An exceptionally large group of physicians was present this year and, as always, was astounded and

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uplifted by the sight of their happy patients checking out the vendor booths and even *dancing a step or two*. DANCING? That's right. The Tiep trio of docs has all the magic of H.C. Anderson fiddlers. They set hands to clapping, feet to tapping, and smiles on all who heard or saw them play. Our guest speakers were wonderful, the vendors informative and generous, but it was the *spirit* of group that made the day so special. What a privilege it was to be part of this wonderful event!



Would you like to see a partial listing of the latest donors to the Chair? They included those by **Kevin Hettich, Sharon O'Hara, Wm. & Shirley Grindrod, Kay Arndt, Susan**

Hesser, Bonny Steele, RN, PhD, Bill Prentice, RN and Sara Casaburi (in honor of Dr. Rich Casaburi), **New Technology Publishing** and **Dr. Brian Tiep**.

Louise Nett RN, Chad Therapeutics, CORF Licensing Services, Respironics, Metro Med, Option One HME, Pharmacia Upjohn, Salter Labs, Apria Health Care, Sequor Technologies, Inc. and Eli Lilly joined **Dr. Petty's Long Beach 500**.

John Boynton of Cockeysville, MD made another generous donation to the Chair, which makes him a **Sustaining Member** (donations ranging from \$1,000 to \$5,000). John called to say that he and his wife have designated a contribution to the Chair into their will. That makes you very special, John! Additional donations from **Dr. Tom Petty, Reta Long, and Dr. Richard & Mary Casaburi** to the **Long Beach 500** also makes them members of this special group. Joining them is **PREP, the Mission Community Hospital Patient Support Group**. They presented their check during the Rally to a huge ovation from the crowd.

Everyone was overwhelmed by their outpouring of support, and good will. The unbelievable number of *99 members of PREP* joined together to contribute enough to earn their group a place in



history. Their engraved name will be on the plaque under “**Sustaining Members**”! It is wonderful people like you who spur us on to work harder and to keep going on those days when things get tough. You can't know how uplifting it is to know how many there are who appreciate what the Chair will mean to all those who suffer from respiratory disease. We thank you for your support, emotional as well as financial. You are wonderful!

Edmund Roth of New Britain, CT again made a very generous donation to the Chair in honor of his sister, Mary Burns. This now puts Eddy in the very special category of **Premier Member**, someone who has donated \$5,000.00 or more. Mary sends her *very* special thanks for this very wonderful bequest.. Thank you, Eddy!!! ♥♥♥



Freda Standeford of Westchester, CA thinks the Oxy-dog is a *great* idea. She would love to communicate with some creative *handicapped* person who would build *her* a cart. She doesn't have a dog but would like it to hold her e-cylinder and attach it to her Pugeot 12 speed bike. Is there some one out there who already has one of these that they have made? If so, let us know. We may get a cottage industry going here. Some of our bike riding patients put their *liquid* oxygen in the basket in front of them. However, that may be much too

dangerous for an e-cylinder. If you had a spill and broke the neck of that cylinder you might launch a guided missile! So, bring on your ideas for an inexpensive cart for Freda.



Janice wrote to ask about using a **harmonica** as a therapy to improve breathing techniques if you have emphysema. That is an interesting question, Janice. Check out our web site for some good breathing techniques, as well as a lot of other good information. A harmonica is a fun way to practice breathing. So is playing on a **kazoo**, which is a lot easier to learn. That is because the player concentrates on breathing OUT. This will not produce any permanent cure however, since emphysema causes a loss of elasticity in the lung which can result in air trapping. It is important that people learn to breathe out 2 or 3 times as long as they breathe in to prevent more air trapping, to allow time to exhale, and to make room for that air that they breathe in.



Rita wants to know what the **recommended number of breaths per minute** is and why **swimming** would make one so winded.

The number of breaths you take per minute depends mostly on your activity level at the time and also on the degree and type of pulmonary disease you may or may not have. If you have emphysema, the loss of

elasticity and air trapping make it important for you to breath OUT longer than you breathe in, usually about 2 or 3 or 4 times as long as you breathe in. That will slow your respiratory rate down a great deal, maybe as slow as 12 breaths a minute at rest or even less when you do pursed lip breathing. However, you need to go by what feels comfortable.

Swimming may make you more winded than other exercises because you are using some of the same muscles that you use to breathe with. Because of the air trapping in your lungs you may find it more difficult to swim underwater but a lot easier to float. Have you noticed this?



Swimming is a great exercise, even if you are on oxygen. You can put your portable oxygen container on the side of the pool, get a 50 foot hose and do laps, exercise or play as long as you wish. This is especially good exercise for those with arthritis or asthma. Don't forget that sun block if you are swimming outside!



Donations continue to come in for the **Mary Nicolas Lynch** memorial Chair donations from **Mr. & Mrs. C. Paul Jones, Geraldine Rutledge, Molly Lynch, Mr. & Mrs. Timothy Lynch, and Bryan McKenzie.**

Other memorial donations were made by **Mary Gallagher** in memory of **Geneva McGrath**. **James Lynch** in memory of **Charlotte O'Brien**, **Mary Burns and the PEP Pioneers** in memory of **Evelyn Bangert and Anna Gage**, and **Betty Ellis** in memory of **Bob James**.

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The following is the presentation that Dr. Thomas L. Petty gave as he concluded the Respiratory Rally for Research at Long Beach Memorial Medical Center on June 22nd, 2001. We reprint it here.

Remember to Live, and Remember to Give

I first addressed a patient care organization known as the PEP Pioneers, organized by Mary Burns at Little Company of Mary Hospital, in March, 1983. The title of my presentation was, "**Remember to Live**".

I encouraged all persons, young or old, with or without any disease or illness, to pursue life to the fullest, and to enjoy each day for what it would bring. I advised against being timid, and encouraged "**age without abdication**". Today, my message repeats this advice and asks everyone to remember to give.

I attended the first rally of this type in 1985. Then, my topic was: "**Humor for the Health of it**". I

pointed out how humor relieves tension, eases breathing, lowers blood pressure, stimulates appetite and sleep, and simply makes us feel better. All humor takes is time, and it certainly is not toxic.

Today, I would like to make a comment about disease. A *disease* is an alteration in the structure or function of an organ system, which may or may not produce symptoms. By contrast, *illness* is the impact of a disease on the person's quality of life as a result of the symptoms, the limitations that the illness imposes, and the treatment that is required.

Beyond disease and illness, there is the predicament that illness creates. Often the predicament results in pain. It is interesting that the first of the four basic truths of *Buddha* is, "*Life is suffering*". *Seneca*, the Greek philosopher, said, "*And what will amaze you more throughout the whole of life is one must learn to die*". We all know that death is a natural end of the human spirit as we know it, yet we know that it is inevitable. We are born and we die, but hopefully, we can get through life without undue suffering. When suffering comes, and can be accepted, it ceases to be suffering. It often yields to joy.

Benjamin Franklin said, "*Those things that hurt, instruct*." This emphasizes the fact that because of problems, we learn and grow both

mentally and spiritually. I cannot separate the two. When patients learn to face problems, they no longer dread them. As each problem is solved, life becomes enhanced. If you cannot face death, you cannot live. Death is simply the flip side of life. You cannot die if you were never born. But, once you are living, it is important to learn, to grow, and to enjoy.

No one can exactly predict the future such as how long we will live. One of my *favorite psalms, number 90*, goes, "*The days of our lives shall be three score and ten years. But if by reason of strength, they may be four score years*". Then the psalm goes on, "*And then the spirit doth takes wings and flies away.*" This is where "passed away" came from.

As *Jesus* said to Nicodema, "*Just as you hear the wind, but cannot tell where it comes from or where it will go next, so it is with the spirit.*" The word spirit comes from the Greek, "spirue", which literally means "breath". Thus, we have "respiration", "inspiration", and "spirometry". "Expiration" at the end of life promises the transition of the spirit in a new realm of experience. Whether or not you believe in a spiritual future, you have already spread your spirit by working, playing, loving, and living. You have extended yourself to your family, and to your friends.

Not everyone at the Rally may

have had an opportunity to make a major contribution to science, music, art, literature, business, medicine, or law. But, everyone can make a special contribution which will enhance society through support of the Respiratory Research Chair and it's first recipient, Richard Casaburi, Ph.D., M.D. The Chair honors two great people: Alvin Grancell and Mary Burns. Both Alvin and Mary are spiritual people. Both have suffered great losses and pain, as I have. But, we have all weathered the pain, and have grown to be better people, and to make greater contributions to society.

So, my plea to everyone at the rally, and to everyone who reads this newsletter, is to please make a contribution to the PERF and to the Chair which these donations will fund. *Remember to live and remember to give.*

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Congratulations to our friends in the **PREP group at Mission Hospital in Mission Viejo, CA.** Mary Burns, and Dr. Brian Tiep had the privilege of joining their party which celebrated the **13th anniversary** of their pulmonary rehab program and support group. Who says 13 is an unlucky number! Reflecting the fine leadership of Jim Barnett, RRT this group glows with good will and the upbeat attitude of a 5 star program. . Would you *also* like the opportunity to be part of this fun group of pulmonary rehab graduates? Here is your chance.

Join Jim and the PREP group as they *again* take to the seas, this time for a **cruise to the Mexican Riviera, 7 days and 7 nights, starting on April 20th, 2002.** You are on oxygen? No problem! Jim will handle the details with the all the experience he has gotten over the years on previous successful trips. **Call Jim Barnett toll free at 1-877-280-2777** to get the scoop on how you can join these seasoned and savvy travelers.



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Roseanne has a lot of questions about proper methods of breathing. She has conscientiously been trying all of them, including chest excursion, belts etc.. What confuses Roseanne is that her husband doesn't feel that any of these techniques help him very much. He just breathes in and out through his nose and feels fine. What is going on here? This is a good observation and worth talking about.

If your husband has no respiratory disease, or impairment, it doesn't usually make any difference what techniques he uses or doesn't use. We suggest different techniques for *you* to help you compensate for the damage to your lungs, which no longer work at full efficiency. He probably doesn't usually need help.

Now, that being said, let me add that if he were a singer, or an actor or an athlete, he too would be training to use more efficient breathing techniques to

get the very optimal physical response from his body.

Pursed lips breathing also can be helpful at various times to people without lung disease, most especially when they go to altitude. The amount of oxygen available at altitude decreases so pursed lip breathing can help those boy scouts who are hiking, or those healthy adults who are skiing, to breathe easier. Done properly it will increase the oxygen level of their body. Yes, even perfect lungs deliver lower oxygen levels as you increase the altitude you are at.



Many rehab programs use a tape or belt stretched around the ribs while practicing breathing to teach chest excursion. To answer some of your specific questions, if your chest expands, causing the tape to need to be loosened, of course it is because you are filling your lungs with air, That is, you are breathing deeply and moving your ribs outward . Pulling the tape tighter as you *exhale* helps squeeze the air out of your lungs and reeducates your rib muscles do the same or to work more efficiently. Eventually they do the work themselves, without the reminder of the belt. You only need to use the tape or belt for a *short* while to get the general idea. You inhale through your nose to warm, humidify and filter the air. Breathing out through pursed lips helps when you are short of breath. It

slows down your breathing, which is very important. It also helps you to breathe out longer than you breathe in, which is also *very* important if you have COPD. You needn't do it all the time, just when you need a little help to feel less short of breath. These techniques should help you to breathe more comfortably. If they make you *uncomfortable*, you are probably working too hard at it! The staff at a good pulmonary rehab program could really help you a lot with some of these basics.

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We conclude this month's newsletter by reporting an event that makes us all very proud. The following is a news bulletin released by the Harbor-UCLA Research and Education Institute (REI) and published in a number of newspapers and several medical journals, including the *Journal of the American Medical Association*. We would like to share it with you.

Richard Casaburi, Ph.D., M.D., has been approved as the first appointment to The Alvin Grancell-Mary Burns Research Chair in the Rehabilitative Sciences. The Harbor-UCLA Research & Education Institute's Executive Committee unanimously approved the appointment of Richard Casaburi, Ph.D., M.D., Professor and Chief, Division of Respiratory and Critical Care Physiology and Medicine at the Harbor-UCLA Medical Center on June 4, 2001.

This five-year appointment marks the first-ever endowed chair at Harbor-UCLA Research & Education Institute (REI). The endowment was made possible by Alvin Grancell, whose late wife suffered from the debilitating effects of chronic obstructive pulmonary disease (COPD), though a number of other individuals have contributed and fundraising to support this research Chair continues.

As Vice President of the Pulmonary Education and Research Foundation for the past 15 years, Grancell is committed to the promulgation of research in chronic pulmonary disease, and rehabilitation of patients affected by COPD. He designated the Institute as benefactor of the endowment based on his desire to facilitate COPD research at REI, which maintains a large and active research base in chronic pulmonary diseases. These diseases include asthma, bronchitis and emphysema, which afflict over 15 million Americans every year. The Chair is also named for Mary Burns, RN to honor her seminal role in developing the practice of pulmonary rehabilitation.

The next newsletter will report on the annual meeting of AACVPR, the American Association of Cardiovascular and Pulmonary Rehabilitation. Watch for it, and stay well! ♥♥♥