



Second Wind

NEWSLETTER

JANUARY 2002

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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Key words-LVS and NETT, CSPR annual meeting, NECA, use of PERF funds, letters

Is it too late to wish you a happy, and healthy New Year? Of course not! It is never too late for a wish like that. Our Japanese friends tell us that that 2002 is the year of O₂ and that it will be *especially* good for all of our friends on oxygen. Sounds logical to me!



Do *you* have an old family tradition of special foods that you faithfully prepare to help ensure health, and happiness in the New Year? Some cultures traditionally have pork and sauerkraut on New Year's Day. All that vitamin C and B must have really helped their health in the old days. Other cultures love lentils, while many of you with a Southern background



firmly trust the benefits of black-eyed peas cooked all day with a ham hock. If you have other traditions that you follow let us know and we'll pass them along next year in plenty of time to help our reader in 2003.

Mary Burns tried two of the three traditions above, just to cover all bases, but she is looking in vain for some magic that will keep away the computer poltergeists for a while. She had her usual computer collapse over the holidays so, if we missed or messed your name on anything, please let us know.

*We didn't miss the names of **Dave Nelson, Linda Burns and Ann Wentink**, who made their contributions*

in honor of Mary. She sends them her very special thanks. ♥♥♥

*Special thanks also to **Chris Garvey and the Pulmonary Rehab program at Seaton Hospital in Daly City, Ca and The Second Wind Group of Mishowaka, IN** for your generous donations. They are really appreciated!*

LincareInc and PERF board member, **Craig Murga**, became members of the **Long Beach 500** with recent contribution to the Chair in the Rehabilitative Sciences. You are members of a prestigious group! Thank you.

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Are you feeling guilty about all the chocolate you consumed over the holidays? Well, we are here to help you feel better, aren't we? A New Year's gift awaits you chocoholics on the last page. Save this one for future guilt trips. It is a special **Letter from Tom** just for you. Read and enjoy, or eat and enjoy. It's your call, but don't miss that last page!



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Donations were made to PERF by Dr. & Mrs. Brian Tiep, Robert Zerfing, Yolanda Weiss, Galdino Salvador, Sam & Vickey Praw, Kathy Witta, Michele Petersen, Pamela Turiello, Ed Thomas, Dr. Bob Fallat, Keith Elledge, Mr. & Mrs. JE. Meneghello, Audrey Samardich, Weldon Kelly.

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We have had lots of phone calls and e-mail requests in response to our brief paragraph on Lung Volume Reduction surgery (LVRS) and the National Emphysema Treatment Trial (NETT). Because of all this interest we are republishing an article that recently appeared in the CTS NEWS of the California Thoracic Society, medical section of the American Lung Association of California. Please contact CTS if you wish permission to reprint this article.

LUNG VOLUME REDUCTION SURGERY FOR EMPHYSEMA: LANDMARK STUDY ENTERS THE HOME STRETCH

*Andrew L. Ries, MD, MPH
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University of California, San Diego*

Despite some recent public and professional confusion from misleading news headlines, the National Emphysema Treatment Trial (NETT) continues to go well at the 19 participating centers and will be enrolling patients through Spring with last randomization scheduled for July 2002. This landmark study, sponsored by Medicare, NIH, and AHQR, is designed to systematically evaluate lung volume reductions surgery (LVRS) in patients with advanced emphysema. More than 1,100 patients have been randomized

over the past 4 years selected from approximately 15,000 screened individuals and more than 3,400 evaluated at the clinical centers. This represents the largest, well-characterized cohort of patients with advanced COPD to date. The trial has already begun producing important insights about the natural history, physiology, radiology, anatomy, symptoms and quality of life assessment of emphysema. Several publications and abstracts have documented important information from pre-randomization data, such as the benefits of pulmonary rehabilitation. Outcome results of the surgical procedure are still not available, however, because investigators remain blinded while the study is ongoing.

One of the important objectives of NETT is to refine selection criteria by identifying particular subgroups of patients who either do-or do not-benefit from LVRS or who are too high risk for the operation. During the study, an independent Data Safety Monitoring Board (DSMB) regularly reviews study results and makes decisions about appropriate protocol changes. It was just such a finding by the NETT DSMB in April, 2001 that led to an important modification of the study, the first major outcome publication, and, unfortunately, some misleading news headlines. In April, the DSMB identified a high-risk subgroup in

which 30-day surgical mortality exceeded 8%, previously determined to be an unacceptable threshold. The high-risk group was characterized by a low FEV1 (less than 20% of predicted) **AND** either 1) homogeneous distribution of emphysema on high resolution CT scan or 2) low DLCO (less than 20% of predicted). Approximately 14% of the NETT subjects were in this high-risk subgroup. Subsequently, selection criteria were modified to exclude patients with these characteristics. In order to publicize these findings as soon as possible, NETT investigators prepared a manuscript accepted by the *New England Journal of Medicine* for rapid release on its website in the summer before actual publication in October, 2001. After posting on the NEJM website, news releases were distributed widely and all participating NETT subjects were notified individually. As the first major finding from NETT, the press release was picked up by media. Unfortunately, headlines in several newspapers highlighted mortality from LVRS in NETT leading many in the public and professional communities to conclude that the study was being terminated because of the negative findings. Even the ATS communications department, in its rush to notify members, improperly indicated that all patients with



severe emphysema were at high risk from LVRS leading to some unfortunate confusion within our own pulmonary community.

What are the lessons we can currently draw from NETT-and from the recently published findings?

1. Regardless of the ultimate outcome and future of LVRS, the NETT study is a success and represents an innovative mechanism for systematically evaluating a new surgical procedure through collaboration of the health insurance (Medicare) and medical research (NIH) communities.
2. The large, well-characterized database of more than 1,100 patients with emphysema will produce important information about emphysema and COPD. For instance, in analyzing prerandomization data, NETT has already documented the effectiveness of pulmonary rehabilitation in patients with advanced COPD through data collected at the 19 NETT clinical centers as well as more than 400 satellite rehab centers.
3. The preliminary findings released by the NETT DSMB identifying a high risk subgroup demonstrate why a study like NETT is important- i.e., in a systematic fashion

helping to refine appropriate selection criteria to identify patients who are either particularly good or poor candidate for the procedure.

NETT is, in fact, still going strong and will be actively enrolling patients through Spring 2002. NETT investigators hope that you will encourage any interested patients to contact one of the NETT centers (Cedars Sinai and UCSD in California) to take advantage of this unique opportunity. Most patients have benefited considerably from the evaluation and rehabilitation activities even before they have made a final decision about randomization. Once NETT concludes randomization in July 2002 and currently scheduled follow-ups through December 2002, data will be analyzed and turned over to Medicare for review and consideration of coverage. Following this analysis, the medical and lay communities will have accurate information about the benefits and risks of LVRS and the appropriate selection of patients.

Thank you Dr. Ries!.



Memorial donations were made to PERF by Marge Spitzel in memory of Louise Ottavi, Kay Arndt in memory of Anna Gage, Michael Gray in memory of Herman and Margaret Gray, Jeanne Barton in memory of Richard, Mary Burns and the PEP Pioneers in memory of Ed Baker, Mr. & Mrs.

Denny Zamberlan in memory of George Richey, Leo Foley in memory of his wife Anna Gage, Jo Anne Lawonn in memory of Anne Lawonn, Lisa Salkever in memory of Henry Smith, and Rubye Richey in memory of George Richey, Jack Bauman and Nancy Carnelius.

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Are you a health care professional whose main interest is pulmonary rehab? Did you plan to go to the cancelled AACVPR meeting in Minneapolis on September 12th? If so, you might be interested in attending the **California Society for Pulmonary Rehabilitation (CSPR) meeting at Long Beach Memorial Medical Center April 5th-6th**. The two-day meeting is *packed* with state of the art information delivered by world-class physicians, practitioners and scientists. *And* the price is right! For two full days of informative lectures you receive 11 CEU's for only \$150.00, if you are a member of CSPR. Add \$55 to that if you are *not* a member for a total cost of \$205.00 How much does membership cost? Only \$55.00, so you don't need to be an Einstein to figure that one out. We have a block of rooms reserved at the Airport Marriott for only \$109 a night for one, or for as many as four who are allowed to share that room at no additional cost. What a bargain! For further information, or the brochure, e-mail Mary Burns at perf@pacbell.net or phone her at (310) 539-8390. We'd love to have you join

us for fun and information at one of the best conferences of the year.

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We were behind the times! In last month's issue we gave you the phone number of **(212) 277-5581** as a source for finding the nearest COPD support group, saying that that the sponsor was a local Asthma/Emphysema Self-Help Group. The newly formed **National Emphysema/COPD Association (NECA)** incorporated in November now sponsors this number. NECA aims to be a membership driven and controlled organization. Their mission statement approved last year is: "To promote empower patients, their families and caregivers to improve the quality of life by (1) providing advocacy, education, and support programs in partnership with compatible organizations and (2) promoting public awareness campaigns to increase research and improve prevention, early detection and care. We'll be telling you more about this group in the future, so watch for further details as we learn more about them.

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Contributions for the Chair were made by Douglas and Margery King, Carol Daley, Don Murphy, Nadine Buntjer, Lillian Cane in memory of Dr. Seymour Cane, Dorothy Tanner, Rose Shields, Georgia Cline in memory of Andy Cline, Louis Rollino in memory of Dorothy, Donnarene Brown, Edith Winning, Jane Martin, CRTT of Holland Hospital in MI, and also Don

Butler in honor of Dr. Richard Casaburi.

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WE HAVE MAIL

Some friends in **Anaheim, CA** wrote a very articulate letter expressing their alarm about a paragraph in Dr. Casaburi's annual update. This paragraph referred to "branching out" to use techniques developed for COPD to help those on kidney dialysis or with prostate cancer, sickle cell anemia as well as children born with heart abnormalities. They were concerned that their donations were being used for these conditions rather than research for COPD, the forgotten disease. *Not so*, but we are SO glad that you wrote to us so that **Dr. Casaburi** could clarify this misunderstanding. Here, in part, is his response.

Dear Friends,

I couldn't agree with you more. The impact of COPD has been sorely under-appreciated and research into COPD therapies have been under-funded. The efforts of PERF have been almost exclusively dedicated to COPD and I have felt honored to head PERF for the past few years. My own research has been focused on finding new therapies for COPD. All of the approximately 10 research projects of which I am principal investigator concern COPD.

I think that there is a distinction that we have not made clear that is causing some confusion. The Rehabilitation Clinical Trials Center does not receive its major funding from PERF. How could it? The salary costs for the technical staff in the Center alone amount to several hundred thousand dollars a year. Expenses of this magnitude are far beyond PERF's ability to support. The funds to pay these costs come from grants we apply for....for example, from the government, the Lung Association and from pharmaceutical companies. PERF has provided some seed money for some of the most important work that could not have been funded otherwise. In some cases, "pilot" studies funded by PERF have lead to much larger grants to investigate therapeutic strategies in COPD.

The Rehabilitation Clinical Trials Center could not succeed without attracting other investigators. For some, COPD is a major focus, but others are interested in other chronic diseases. The research projects they have initiated have added to the breath of activities going on in the Center, and are helping to financially support the overall enterprise. There is a lot of cross-fertilization going on....progress in one area leads to progress in others. I view this as a highly positive step, but do not see it as diluting our focus on COPD.

I can assure you that your donations to PERF, which are greatly appreciated, are devoted to respiratory disease. I would like you to believe that the Rehabilitation Clinical Trials Center has one of the most concentrated clinical research programs in COPD in the world.”

(Signed) Richard Casaburi,
PhD, MD

We think it is wonderful that you wrote to us and hope that anyone else who has any concerns about anything that we write will follow suit and also communicate with us by letter, by phone, or by e-mail. We like to know that you care, and that you are reading all this information that we try to put together for you! Thanks for letting us help clarify the confusion.

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Mat in NYC asked if we could assist a relative in Sweden get help for his emphysema. Besides newsletters and booklets that we were able to provide, we contacted **Margareta Emtner, PhD in Upsala, Sweden.** (Margareta was a Fulbright Scholar who worked at Harbor-UCLA for a year doing research on exercise and oxygen. More on her exciting study later!) She gave us the name of a caring physician in the patient’s hometown of Gothenberg. It’s wonderful to have a network of friends around the world, for us, but also for you.

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And speaking of friends in other parts of the world, **Tetsuji Watanabe** wrote to tell us that a very successful **Lung Day Forum** was held in **Tokyo, Japan** in November. The forum was sponsored by the Ministry of Health and Labor, the Japanese Pulmonary Society and the Yomiuri Newspaper Company. (This, he told us, is a daily newspaper with over a million readers, the largest in the world. I wish we could get that kind of publicity and support here in the States!) Film clips of talks given by Dr. Casaburi and Mary Burns started off their day. Dr. Kida, who has often visited us in Torrance, gave a speech about cessation of smoking, as well as referring to the high intensity exercise research being done at Harbor-UCLA by Dr. Casaburi.

This e-mail was followed by a box of beautiful Japanese calendars and some Oxy-dog t-shirts, via Fed-ex. You may recall that the oxy-dog is a device the Japanese are using to have their dogs help carry oxygen when oxygen users go for a walk. An earlier story we did on this excited a fair amount of mail. Mr. Watanabe ended his e-mail by saying how much he enjoyed the Second Wind. And we would like to add how much *we* enjoy hearing about the progress in helping COPD patients in Japan!

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From Northern Territory, Australia we have had some wonderful correspondence with Kat, as she is

known on the Internet. She especially likes some of the old letters from Dr. Tom that she has been reading, saying “how good it feels to ‘hear’ a health professional express so much understanding and caring”. Kat is pretty much alone in a fairly remote area. She says she almost cried with joy when she first found so much information and support on the Internet and with the COPD Support Group.

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But not all of our correspondence is from other parts of the world. We get a lot of mail from the various states. We especially would like to congratulate **Linda from NYC** who has made remarkable progress just with sheer determination and follow-through. She had many questions about her oxygen needs and the meanings of all her tests. The lesson all of you could learn from Linda is the importance of getting your physician to communicate and explain things to you. It is your body and you have a right and a need to know what is going on if you are to be motivated to do something about your health. Do you have a physician who tells you that there is nothing else that can be done to help you? Possibly that is so, but you certainly should then feel free to insist on a second opinion from a pulmonologist of your choosing. And you most certainly could request a referral to a pulmonary rehab program. If you aren’t a candidate for rehab the staff at the program will let you know why. Sometimes, even if not a candidate for a full program, you might

get help with breathing retraining or other specific needs. Unless you have Alzheimer’s and can’t remember instructions from one minute to the next, or are unable to be out of bed long enough for the program, you should be eligible for some help for your respiratory problems. Of course, that is assuming that your HMO and insurance cover this therapy, but that is another story for another day!

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Homer, AK isn’t as remote as the Northern Territory of Australia but it is a different world from NYC. **Jim** uses the phone, rather than the e-mail, to periodically get some moral support on smoking cessation and advice on safely increasing his activity. Keep up the good fight, Jim!

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We are always pleased to try to answer your questions and help you but every once in awhile it is also wonderful to hear from someone like **Terry Cass**. Terry works in **Cardiopulmonary Rehab at the Riverside Medical Center in Kankakee, Illinois**. She often drops us a few words of specific appreciation for an article, and for the “Letter from Tom”. Terry keeps the newsletters in a binder so that her patients can continue to enjoy them. I’ll bet they also enjoy you, Terry.

We would like to wish Terry, all of the patients at Riverside Medical, and all of you, our readers, a New Year of learning, laughter and livelier lungs. Bless you all! ♥♥♥