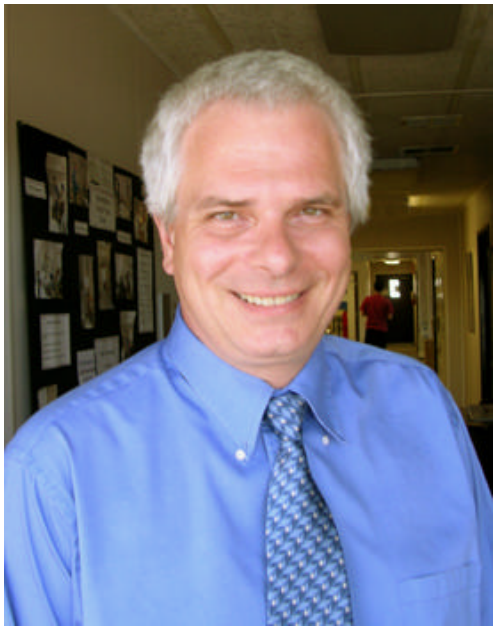
Second Wind
NEWSLETTER

AUGUST 2004

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.

KEY WORDS: Janos Porszasz, MD, PhD; 16th birthday of PREP; Japanese patient support groups; Dr. Petty's Independence donation campaign; Adventures of an Oxy-phyle; Update on Vitamin E; FAA proposed rules on oxygen concentrators on planes: COPD/Alpha 1 Education day Oct. 2, 2004 in Carson, CA



Janos Porszasz, MD, Ph.D.

If you looked at distinguished names listed under PERF Board of Directors, you will see that we have added that of **Janos Porszasz, MD, PhD.** Does the name sound familiar? It should, since Janos, as he is known to colleagues and patients alike, is also our web master. Janos was an Assistant Professor at the Medical University of Pecs, Hungary when first recruited to Harbor-UCLA 1991. He was here as a Research Associate while completing research necessary for his PhD. In 1995, he returned to Hungary as head of the Department of Physiology and Ergonomics at the National Institute of Occupational Health in Budapest. Two years later, Dr. Casaburi visited him in Budapest and lured him back to Harbor-

UCLA. Since then, he has had a faculty position at UCLA and is now **Technical Director of the Rehabilitation Clinical Trials Center**. He returned to the States with his lovely wife, Suzanne, also a distinguished PhD scientist, and his pretty daughter Judit. In addition to his scientific expertise, Janos is a fine musician and a professional level photographer. Whew. Can we pick them or can we pick them! Janos has always been a strong supporter of PERF. We are honored he has now made that relationship official. Welcome aboard, Janos!

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We like birthday parties! We *especially* like birthday parties when they celebrate the success of one of our very favorite patient groups. July 9th marked the **16th** Birthday of **PREP, the patient support group at Mission Community Hospital**, in Mission Viejo, California and what a gala celebration this was! The local Holiday Inn banquet room was bursting at the seams with almost 200 happy, chattering celebrants, non happier than **Jim Barnett, RRT, RCP**, their beaming leader. Jim told the audience he had the best job in the world; he actually got *paid* to do pulmonary rehab, a labor of love! With Jim's positive attitude as an example, it's small wonder that the faces of his graduates reflected his, with smiles on each and every one. Mary Burns was honored to again be a guest of this great group. She is planning to show some of the many pictures taken there, at the *next* birthday party she has been invited to attend. That attendance will involve more than a one-hour drive down the freeway since it is all the way around the world in Tokyo, Japan! The J-Breath, a national patient support group, will be celebrating their 5th birthday. They are very interested in connecting more with American patients and have asked Mary to talk to them about this. A start towards this goal was made when Jim's group gathered

to extend greetings to their Japanese counterparts by holding up a huge multi-colored banner reading **KONNICHIWA**. This is a greetings meaning something like "Good day". Mary planned to use "Konnichiwa" as the opening slide of her talk, but has just learned the Japanese party will be at night! With paint stained fingers she was heard to mumble something about next time sticking to a generic "Hi".
Japanese patients are very interested in how American patients handle oxygen with work and play, yet still are motivated to enjoy life with COPD. They want to network more! If you have any ideas you would like to share with them, Mary would love to hear from you.

Dr. Petty's adjustment to oxygen is about as good an example as you can find, though his problems are not due to COPD. While his physical activities have been sorely limited this past year there is nothing wrong with his enthusiasm or his ideas. They are as boundless as ever, as you could see by his **Independence Donor** campaign, over the 4th of July. He decided to be an "**Independence Donor**" giving $230.00, one dollar for each year of our country's existence, as thanks for his improved health. He suggested that others who have benefited from Pulmonary

Rehabilitation, oxygen, etc., and who also experienced the restoration of their personal freedom, join him. He wanted to celebrate with a gift to PERF, where this support would help others in *their* quest for freedom. How is this campaign going? So far, he has raised $3,000.00, much of it donated in his honor. Another $1,000 is pledged. Ever the optimist, Dr. Petty was aiming for $5,000, and who knows. He may yet reach his goal. We sincerely thank those of you who joined him in his celebration. This month that includes, *Emily Hansen*, *Mary Ellen Weger*, *Bonnie McCarthy, Iris Patton, Philip Whiting, Jerry Gorby, John Raymond, Amy Walker, and Nancy Moore* who joined previous donors *and* Dr. Tom Petty with their Independence Day donations. (We never cease to be amazed by all you good people!)

Being on oxygen 24/7 also inspired him to write his latest book, **Adventures of an Oxy-phile**. This 96 page booklet is *crammed* with information that every oxygen user should have available. Besides the scientific basis for LTOT (long term oxygen therapy), it contains Dr. Petty's personal adventures, beginning with his first studies of ambulatory LTOT in 1965. It continues with his observations "from the other end of the stethoscope" when he also became an oxygen user. Some of our readers contributed personal vignettes on their oxygen experiences. Various oxygen systems are compared in detail along with information you won't find in other books written for the layperson. Lots of pictures add to its appeal. It takes someone like Dr. Petty, on oxygen himself, to know what oxygen users want to know and should know. *This is a book every pulmonary rehab program and support group should get for their library **now**, while they are available!* Dr. Petty tells us that Puritan Bennett has 10,000 of these that they will distribute free. They are also available from the AARC (American Association of Respiratory Care), 9425 N. Mac Arthur Blvd., Irving, TX 75063. Phone 872-243-2272. Dr. Petty thinks that AARC is selling them for a nominal fee. Mostly, he is hoping these booklets can be widely distributed to meet their intended purpose of being informative, enjoyable and inspiring. Who else could better achieve this than Tom Petty!

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Giannina Donatoni made a donation in memory of her father Jerry and to also commemorate her parents' 50th wedding anniversary. What a very special gift for your mother, Giannina. We are touched. Gene Pirazzi also made a donation to honor the 50th wedding anniversary of Bob and Carolyn Hoffman.

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If you are following the story of cross-country progress of oxygen user Mark Junge, there has been a URL change. The new URL is *www.heliosfreedomtour.com*. As we write this, he is in Salt Lake City, Utah. A fantastic accomplishment, Mark, and we wish you continued success!

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There has been a great deal of interest expressed in the series on herbal medicine by Dr. Herb Webb. To say that we've also had interest about the information on Vitamin E in last month's installment would be an understatement! Dr. Webb was kind enough to draft a written answer to the many questions he received after his article on vitamin E and after a talk he gave to his patient group.

UPDATE ON VITAMIN E

by Herbert Webb, MD Pulmonologist

Dr. Herbert Webb *is a pulmonologist in private practice in* ***San Pedro, CA,*** *and an illustrious graduate of the program at Harbor-UCLA. He is Medical Director of the* ***San Pedro Peninsula Hospital Pulmonary Medicine Department*** *and their* ***Pulmonary Rehabilitation program.*** *He wrote this article for their Better Breathers' Club newsletter. With the gracious permission of* ***Editor Kris Brust, RN, and Dr. Webb,*** *we share it with you.*

RESEARCH TERMINOLOGY

Epidemiologic study: what causes the disease?

Preventative study: what prevents the disease?

Prospective study: epidemiologic study with respect to medical, social and environmental factors.

Retrospective study: records are investigated and patents are interviewed AFTER they get the disease.

Randomized study: subjects are assigned to groups by a toss of the coin, avoiding inadvertent selection bias.

Placebo: inert substance used by researchers to substitute for the medication being studied; a "sugar pill".

Double blind: neither the researcher or the subject know whether the subject is getting the placebo or real medicine; this prevents the researcher from telegraphing hoped-for results to the patient.

Many studies have now documented the dramatic difference between *epidemiologic* evidence and interventional or primary prevention studies. Epidemiologic evidence indicates that diets high in carotenoid and flavenoids found in food such as fruits and vegetables, as well as high serum levels of vitamin E (alpha tocopherol) and beta carotene, are associated with the reduced risk of cancer, heart disease and death. However, the result of *interventional* or *primary prevention* studies indicate that there is no benefit to antioxidant agents given as preventative agents in *prospective, randomized and double-blinded placebo prospective* trial basis.

The most dramatic such evidence comes from the famous Finnish study of vitamin E and Beta carotene on the incidence of lung cancer and heart disease in Finnish male smokers. This study evaluated 29,133 male Finnish smokers age 50-69 years. They were given one of four combinations: either vitamin E at 50 mg per day alone, or a placebo. These individuals were followed up for 5 to 8 years. Vitamin E had no effect on the incidence of lung cancer, although it did seem to decrease incidence of prostate cancer. Beta carotene resulted in a dramatic <u>increase</u> of lung cancer. Numerous other studies have shown no benefit of beta carotene or vitamin E on the incidence of ischemic heart disease. **Beta carotene is definitely no longer recommended as a supplement.** There were more deaths in those taking the beta carotene, but no change in the mortality rate in those taking vitamin E. There was a slight increase in incidence of hemorrhagic strokes (bleeding into the brain) in those taking vitamin E. Numerous other studies have documented that there is no benefit on the incidence of cardiovascular events such as cardiovascular death, myocardial infarction (heart attack) and cerebrovascular infarction (stroke) by taking vitamin E. Large studies such as the Hope Trial with 9,541 patients, the Heart Protection study with 20,534 patients, and the GISSI Prevention Trial with 11,324 patients all showed **no**

benefit from taking supplemental vitamin E on most cardiovascular events.

Vitamin E might be beneficial to chronic renal (kidney) failure, hemodialysis patients in terms of preventing fatal or nonfatal myocardial infarction (heart attack), or in patients with a rare form of angina pectoris called variant angina pectoris or vasospastic angina.

There were some studies comparing antioxidants (vitamin E plus vitamin C plus selenium) to a conventional statin type medicine (Zocor) on preventing heart disease. Statins were studied with and without niacin and then in combination with the antioxidant vitamins. The findings were that the Zocor or statins plus niacin had a dramatic benefit on preventing coronary artery disease. So, the statin drugs and niacin work. But the antioxidant vitamins actually negated that value and produced a negative result! What happened?

Vitamin E converts good cholesterol into bad cholesterol!

It appears that vitamin E converts a *good* fraction of the HDL cholesterol (happy cholesterol) into the *nonbeneficial* unhappy form of HDL2. **So, in summary, there's no reason to take vitamin E for the prevention of heart disease unless you have a very rare form of angina called variant or vasospastic angina.**

Vitamin E has been studied in numerous settings to see if it will prevent other cancers. It doesn't have any effect on prevention of colon cancers or breast cancer in women. So far, it has shown questionable benefit in preventing aggressive metastatic (spreading) prostate cancer. And, frustratingly, the data is not clear as yet as to whether vitamin E may protect against the development or progression of Alzheimer's disease.

The influence of vitamin E supplementation on the occurrence of respiratory tract infections is very important information for our COPD patients. Two large randomized placebo controlled studies found no reduction in the incidence of respiratory tract infections in hospitalized elderly patients receiving daily vitamin E supplements. Furthermore, in one of these studies, in those experiencing respiratory infections, those who received vitamin E supplementation at 200 international units per day had a significantly longer total illness duration (19 versus 14 days). To add insult to injury, they were even sicker than the other patients with more symptoms, higher fever, and more restriction of activities.

In summary, when COPD patients came down with respiratory infections, the folks who took vitamin E got sicker and stayed that way a full five days longer.

A major interaction of vitamin E with therapeutic medications includes the dangerous interaction of vitamin E in high doses with Coumadin anticoagulants, which leads to an increased incidence of hemorrhage in the brain.
To summarize, it appears that there is little evidence, except in certain niche situations, for taking vitamin E for any

benefit. Perhaps vitamin E in small doses has little negative side effects or complications. I do not recommend vitamin E supplementation at this time. Numerous experts in the field concur with me.

We would all like to thank Dr. Webb for this valuable information and for answering so many of the questions that we received. We would also like to share with you the following information provided by Kris Brust, RN.

Those of our readers who wish to review the research themselves will find the reference listings are about an inch thick! For reviewing the raw data, here is a good start:

New England Journal of Medicine 1994; 220-1029: "The effect of vitamin E and beta carotene on the incidence of lung cancer and other cancers in male smokers"

Journal of the American Medical Association 2003; 290: 476 "The ATBC Study Group. Incidence of cancer and mortality following alpha tocopherol and beta carotene supplementation: a post intervention follow up"

Lancet 1992; 340: 1124 "Effect of vitamin and trace-element supplementation on immune responses and infection in elderly subjects"

New England Journal of Medicine 1997; 337: 408 "Antioxidants and atherosclerotic heart disease"

Annals of Internal Medicine 1995; 123: 860 "The antioxidant vitamins and cardiovascular disease; a critical review of epidemiologic and clinical trial data"

Thanks, Dr. Webb! This series was great and we hope we can get you to contribute other articles to the Second Wind the near future.

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We have some important information for all of you from **Mr. Gary Ewart** (ATS lobbyist) and members of the **US COPD Coalition Policy Subcommittee** working on the **Congressional COPD Caucus regarding FAA rules on Portable Oxygen Concentrators.** Your comments are requested by **August 13, though there have been many requests to have this extended to October 14th.** A copy of the FAA ruling and this material will be posted on the US COPD Coalition Website at www.uscopd.org and also on the PERF Website at www.perf2ndwind.org. We apologize for getting this information to you so late. If you subscribe to enews we will see that you get the information in a timely manner.

TO: US COPD Coalition
Subject: FAA Proposed Rule on Portable Oxygen Concentrators (POC)
DATE: 7/15/04

Great news! On Wednesday, July 14, the **Federal Aviation Administration (FAA**) published a proposed rule that would create a **Special Federal Aviation Regulation** (**SFAR**) to allow portable oxygen concentrators on civil airplanes. Portable oxygen concentrators work by the same principle as their larger cousin, the stationary concentrator, extracting oxygen directly out of the air. Portable oxygen concentrators have fairly high electricity consumption and must run either off batteries or must be plugged in to a wall or automobile socket. These devices are perceived as posing a lower aviation risk than either oxygen tanks or liquid oxygen. While there are still issues that

need to be discussed, the publication of the rule represents a big step forward for patients using supplemental oxygen. The US COPD Coalition should feel pleased about its efforts to get FAA to move on this issue. The FAA is seeking public comment on the proposal. **The deadline for public comments is Friday, August 13, 2004.**

Attached is copy of the proposed rule.

In general the rule would allow the use of **Portable Oxygen Concentrators (POCs**) under the following conditions

1) the POC does not interfere with airplane electrical, navigational or communication equipment
2) the POC must be turned off when the cannula is not in use
3) the POC user or traveling companion, must be able to hear and see all warning indicators and respond appropriately
4) the POC cannot be operated within 10 feet of an open flame or burning cigarette
5) the POC intake filter must not be blocked
6) the POC must be stowed under the seat in front or in other secure location
7) patrons using the POC cannot be seated in the emergency exit row
8) the POC must be free from petroleum, grease and oil and be in good working order
9) the POC must be meet filter maintenance requirements (filters to be manufactured maintenance every 3000 hours of use)
10) the pilot of the flight must be informed of the POC on flight
11) the POC user must have physician statement the specifies the use of and oxygen flow rate
12) only lotions and salves approved for use with oxygen can be used by the POC user
13) the POC user must have enough batteries to power the device through the flight duration and additional "reasonable or anticipated delays."

As written, the draft rule applies only to the AirSep LifeStyle portable oxygen concentrator. However the rule states that the **Inogen product is under review**. The rule essentially creates a pathway for other products to be reviewed and approved under the SFAR.

The FAA is seeking public input on the following questions:

1) Should the aircraft operator be required to inform the user about the availability of electrical outlets suitable for the portable oxygen concentrator?
2) Should the user be required to carry batteries for the duration of the flight including reasonable delays if there are electrical outlets available on the flight?
3) Are the meanings of the terms ''anticipated delay'' and ''reasonable delay'' sufficiently clear?

There are additional issues that I would recommend the community consider commenting on, including:

1) Should air carriers be required to allow POCs on civil air travel? As drafted the rule allows air carrier to use POCs on board. The rule does not require air carriers to allow travelers to use POCs.
2) Should FAA issue a blanket ruling on the POCs and their impact on airplane electronic,

communications and navigational systems? As drafted, the POCs are still required to be tested on a model by model basis for all airplanes
3) Should passengers traveling with POCs have priority access to on board power sources?

In a related rulemaking under the Air Carrier Access Act, the Department will seek comment on whether carriers must permit users of AirSep portable oxygen concentrator to plug their devices into available onboard power outlets, consistent with FAA safety rules related to electronic devices.

I welcome your input on the proposed rule. While there are still issues that need to be resolved, this rule (and the expected rule from the Department of Transportation) represents a significant improvement in the travel options for patients using supplemental oxygen. This rule would not have happened were it not for the sustained advocacy of patient and provider community on this issue.

Since this document was published on the Internet, many thoughtful critiques have been written. The detailed critiques of oxygen users who travel often, and know first hand the problems of flying with oxygen, were especially impressive. We wish we had room to publish some of them in detail. And we hope the deadline for discussion is extended until October 14th so that all of their concerns are addressed. Watch for next month's newsletter for further developments.

Save this date!

Saturday, October 2, 2004

Join us at an outstanding ***free*** educational event at the Hilton Carson Plaza Hotel in Carson, California, right off the 405 San Diego Freeway.

The Los Angeles Biomedical Research Institute *at Harbor-UCLA Medical Center will present* **COPD/Alpha-1 Education Day** *from 8:30AM - 4::00 PM.* There will be 2 separate tracks: one for patients and one for physicians and other health care providers who may also receive CEU's for the lectures attended. Come and listen to lectures by authoritative speakers who will present up-to-date information on the diagnosis and care of COPD and Alpha-1 patients. Free box lunches and coffee breaks will be provided as you cruise the many exhibits. The full program with the confirmed list of speakers will be ready soon. Rich Casaburi and Mary Burns are among the local organizers and we are in the process of recruiting a fine group of speakers.

Reservations are absolutely necessary. To make them, call Cindi Hacker toll free at **(866) 229-2768.**

Snowdrift Pulmonary Conference

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Senior Moderator

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August 2004

Dear Friends:

A Little Wine is Fine!

A number of articles about the benefits of red wine receive a level of encouraging emphasis that tends to catch our imagination. Recently the *Journal of the Wine Spectator* reported that California Pinot Noir as well as other red wines, and the red wine components known as resveratrol, are effective killers of certain bacteria known to infect the lungs. These wine components are known to be potent antioxidants and have been considered healthful in asthma and related disorders. A body of accumulating evidence in a respected medical journal, *Atherosclerosis* , indicates that wine can be "bacterial busters" and deals with some of the common infectious processes of the lungs. These bacteria can affect the arteries of the heart and contribute to heart attack. But the mechanism by which wine, resveratrol and other polyphenols exert their biological effect in heart and lung disease has not been completely worked out. It is a fact that lots of people have been drinking wine for a long time.

Many marvel over the "Mediterranean Diet", which includes high fat and carbohydrates but seems not to cause the same devastating cardiovascular complications as seen in this country. The protection is attributed largely to the high consumption of wine. Many Mediterranean cultures drink wine at all meals. This is a key component of their regular diet. Maybe they know something that we don't know.

I marveled one day, when having lunch at the train station in Florence, Italy when an old gentleman rode up on his bicycle, got his tray of bread and cheese and a liter of wine. He read his newspaper, ate about half a loaf of bread, a pound of cheese, drank the entire liter of wine, got back on his bicycle and rode swiftly into the crowed streets. I wondered what his blood alcohol might be! But that isn't the point! He was happy, content, enjoying life and rode off with a smile into the crowds.

In any case, wine is pleasant, stimulates the appetite, and often provides conviviality in conversations, which become "lubricated" by products of the fermented grape. My own view is that wine is healthy and should be taken regularly in moderation. I do not recommend that non-drinkers suddenly take up wine consumption and never advise use of alcohol to the extent of any noticeable impairment.

I'll be in touch next month.

Your friend,

Thomas L. Petty, M.D., Professor of Medicine
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