



MARCH-APRIL 2003

*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, or 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.*

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**Polynesia, Cruises, New books, AirSep concentrator, Cleaning supplies, Retinoic Acid, Dr. Petty and Ron Peterson, Smoking cessation, Electronic Second Wind**

Did you miss us last month? Your editor took a long dreamed of vacation to French Polynesia and was snorkeling in the crystalline waters instead of pounding the computer. Are Tahiti, Bora Bora and those other fabled islands the place for *your* perfect vacation? Proceed with caution and take a *long* look at what you will be getting into before deciding.



In French Polynesia there are two seasons; hot and humid, and *very* hot and humid. The best months are reputed to be from June until October. With less rain, the bug population decreases, and the trade winds gently blow. You would still want to make sure that you have an air-conditioned hotel room (with screens!) unless you are one of those rare people

who enjoy the dog days of summer. Scenery is spectacular! The lagoons surrounding all the islands ensure calm water that is shallow many, many yards from the rocky shore. The sea is very warm but the sun even more so. Sunburn is a huge hazard, even with #45 sunscreen, but if you cover up carefully, you can enjoy the unbelievable display of vibrantly colored fish either from glass bottom boats or by snorkeling. There are also lots of reef sharks and Moray eels but with such a smorgasbord of tasty fish available they aren't too interested in the human species. Snorkeling can be as active as you wish to make it, and it is appropriate for many with pulmonary disease. Did you know that the air trapping in lungs that is a hallmark of COPD actually helps you to float?

Cruises are a wonderful way to sample these fabled islands in comfort,

especially for those with physical limitations. Don't let your COPD stop you from enjoying life. There are lots of potential adventures out there and, as Dr. Tom Petty says, "You can't stop getting old by any acceptable method, so you might as well enjoy the ride!"

One "ride" coming up next March 21<sup>st</sup> 2004, is a 15-day cruise to the



Hawaiian Islands with **Jim Barnett, RRT of Mission Community Hospital in Mission Viejo, CA.** Jim is as

experienced in directing successful cruises and trips for his group as he is in leading his outstanding pulmonary rehab program. Are you interested in joining this fun group of people? Call Jim at **1-949-365-2106** for further information.

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### **HOT OFF THE PRESS!**

***Breathe Better, Live in Wellness-Winning Your Battle Over Shortness of Breath*** by **Jane Martin, RRT** is newly on the market. Her first book was the well-received ***Inspirations: Stories of Breathing Better and Living Well***. Call 1-877-289-2665 or go to [www.buybooksontheweb.com](http://www.buybooksontheweb.com) if you want to buy one at \$17.95. If your group orders 6 or more they are only \$8.98 a book. Call 1-877-BUY-BOOK (877-289-2665) for information on this bargain. Nice job, Jane!

Have you ever seen a copy of **Breathin' Easy** or accessed its website at [www.breathineasy.com](http://www.breathineasy.com)? If so, you know what a treasure this book is for the traveler with respiratory problems.

**Gerry Gorby** is the energetic, fun loving editor of this labor of love. Being 24/7 oxygen dependent for many years has not stopped Gerry, and his lovely wife Eleanor, from roaming the roads, skies,

seas and rails. He wanted to share his know-how and experiences with others on oxygen, and the result has been **Breathin' Easy**, now on its 7th edition. It is a must for any pulmonary rehab program library and a bargain at only \$28.60, shipping included. Call 1-888-999-7636 for further information.

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**Dr. Tom Petty** tells us that he is looking at a new 9.75 pound battery powered oxygen concentrator developed by **AirSep**, and called "**Life Style**". It provides an F<sub>I</sub>O<sub>2</sub> of 95% at up to five liters per minute. Translated into English...that's good! There is a rechargeable battery, which lasts 45 minutes. It recharges again in two hours using AC or DC currents as well as the cigarette lighter in the car. (*At last*, a use for the cigarette lighter!) When not being carried around, it can be continuously recharged in car, home, or office. It uses a converter, is easy to look at, and is sold by dealers directly to patients. Since it costs between \$4,000 and \$5,000 it may be a possibility for the affluent but is not yet much of an option for people on a fixed low income. The FAA may soon approve it for use on an aircraft as a "battery powered breathing assister." It does not change the level of oxygen in the cabin of aircraft, of course. **Gerry Gorby** gave the *Life Style* a test run on his 8,600 mile cross-country driving trip and said he loves it. *One problem with this unit, besides the short battery life, is that it cannot be switched to continuous oxygen, which is a real disadvantage for many of our patients.* Never the less, Dr. Petty cautiously thinks the technology is a real advance. Another inventor says he is bringing Dr. Petty a 7-pound prototype concentrator in late April. We will let you know his

evaluation of the potential of that unit. Keep reading and we will keep you posted on what is new!

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Congratulations and best wishes to **Genny Schaniel**, who successfully graduated from the great rehab program at Grossmont Hospital in La Mesa, CA. We knew you could do it, Gen!

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**We Need Your Help!** C SPR (the California Society for Pulmonary Rehabilitation) would like to keep an up-to-date listing of all support groups in the state of California. Will you help us by calling 1-310-539-8390 if you think that your group is not yet listed? There are a lot of physicians, as well as folks with pulmonary disease, who could benefit by your phone call and this listing.

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**We get mail.....**Jim writes that he was recently in the hospital with pneumonia. While receiving an inhalation treatment from a therapist, a housekeeper sprayed a 5-foot area of the floor near him, which was covered with blood. He was told that it was a sterilization cleaner with an inert propellant which concerned him. He wanted our opinion and an Internet connection to check on the safety of the spray.

If you know what a product is, you can check the **Material Data Safety Sheet** on the Internet for detailed information. This is the official site for verifying if a product can cause any harm. Hospitals generally will not use chemicals that can easily provoke reactions in sensitive individuals, even though they need to be extra cautious about cleanliness, germs *and* blood contamination. (We *hope* it wasn't your blood!). Housekeeping departments are

monitored carefully on the products that they must use. Blood on a floor is a particular source of potential problems. However, it is doubtful that a brief exposure to a spray such as this can have long lasting consequences. We *do* sympathize with the concern you felt, however, when you were already short of breath and fighting for air. Odors of any kind can cause some temporary discomfort but *perfume* is probably the worst offender. Nurses, therapists, and sometimes even visitors, are warned about using scents of any kind, when around respiratory patients. We hope you are now up and about. And if you are one of those unfortunate individuals especially sensitive to odors, don't forget those you *yourself* may be using! Try using unscented soaps and aftershave lotion when you are trying to scent-proof your environment. Good luck!

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Congratulations to **Warren Mittelholz** and the others in his class, recently graduated from one of our favorite pulmonary rehab programs at **Long Beach Memorial Hospital, in Long Beach, CA**. Warren apparently told everyone in the class that they *must* subscribe to the Second Wind. We modestly decline to disagree.

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**John wrote** asking about the status of Retinoic acid research, and how he could volunteer for stem cell research on the lung. We referred this on directly to Dr. Casaburi. He answered:

Retinoic acid research is proceeding with a number of animal and cell culture studies and one modest-sized human study now underway. The initial very small human study showed no benefit...but

the study design may not have been optimal. The best news is that at pharmaceutical companies are working to find "better molecules" related to retinoic acid and seem committed to putting in the money required to test their effectiveness. **It** will be some years before we can be sure that this approach is successful. I have no knowledge of stem cell approaches being used for therapy of patients with lung disease.

I hope this is of help.

Rich Casaburi

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Jeanne Rife and the PEP Pioneers made donations in memory of Florine Love, Patricia Redmon, Donald Kellog and Lucille Miricle, Tjaakje Heidema in memory of John Heidema., The ING Community Matching Gifts program made a donation. Kevin Hettich made a donation to the Chair in honor of Mary Burns. (Thanks, Kevin! ♥♥♥)

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How many years ago did you first figure out that staying physically active made you healthier and kept you out of the hospital? Well, you were way ahead of the game!. A recent study published in prestigious medical journal Thorax (2003;58:100-105) again proved what all of us know. Exercise works! The headline reads ***Remaining Physically Active Seems to Reduce Hospital Readmission for COPD***. Many of you already know this but it's nice to see it formally acknowledged.

### **Walden Pond on High**

*By: Thomas L. Petty, M.D. and Ron Peterson*

Henry David Thoreau's classic and yet poignant story of his sanctuary at Walden Pond prompts this story. Thoreau went to Walden Pond to seek nature. After vividly describing the beauty of Walden Pond, Thoreau died of tuberculosis at the age of 42. Today a much more common pulmonary disease is COPD. Although COPD is most commonly thought of as tobacco-related chronic and asthmatic bronchitis, almost all patients with COPD have a substantial emphysema component. It is *emphysema* that results in loss of elastic recoil, hyperinflation, air trapping, dyspnea and disability. COPD is now the only disease in the top ten that is increasing in prevalence and mortality. In 2003, 125,00 people in the US will die of COPD, rising to the fourth most common cause of death. *More women than men died of COPD in 2000.*

**Ron Peterson** began smoking at age 13 and rapidly became addicted. In spite of cough and some shortness of breath, he loved living in the Rocky Mountains. In his early 40's, he and some of his engineer friends built a small cabin near the old mining town of Idaho Springs, Colorado, about 40 miles west of Denver. Ron had purchased an old mining claim at 9,000 feet and wanted to live in an area far from the air pollution of cities, and the complexities of modern society. But he had to abandon his plan in his early 40's when rapidly progressive emphysema, due to smoking, made it impossible for him to live at such a high altitude.

Rapid debilitation followed and Ron lost his job due to progressive exercise intolerance. By age 50, he was receiving social security disability. Ambulatory oxygen and an exercise program during a pulmonary

rehabilitation program helped him at first, but later progressive physiological impairment overtook him. He finally quit smoking at age 51 when he coughed so hard he blacked out after a single puff of cigarette smoke. Miraculously, he became a candidate for lung transplantation, which was successfully accomplished at the end of 2000. Now Ron is living happily in an observatory at a 9,000-foot elevation. He enjoys life and works with teens about smoking. He wants teens that have made the mistake of starting to smoke cigarettes convince other teens not to smoke or to quit. Ron has made a powerful tape, *Teen Smokers Speak Out*, which is being widely distributed and is available for viewing and downloading on the Internet at <http://www.geocities.com/ronaldpeterson.geo>

While Thoreau went to Walden Pond to observe nature, Ron went to the Rocky Mountains and his Observatory to live. *The following is Ron's story, which explains his zest for living.*

**8-7-02:** Helping others to avoid becoming addicted to the nicotine in cigarettes has been the focus of my life for 5 years. I know first-hand how harmful cigarettes can be to your lungs and am alive only because of the miracle of lung transplantation. Unfortunately, there are not enough donor lungs available and only about 1 in 2000 who need a lung transplant receives it; the other 1,999 die. As I continue living, my lung disease peers die. It has been my experience, as I became acquainted with the many stages of lung disease, from pre-diagnosis of emphysema to post transplant care, that a great many very talented health professionals are in place to care for us after we contract lung

disease. These professionals are trying to prevent us from contracting lung disease in the United States by preventing us from starting to smoke. They are very successful (about half as many youth in the US smoke as in the rest of the world), but are hampered by lack of funding. The vast majority of the money from the tobacco settlement (about \$265 Billion) is being spent for non-tobacco prevention purposes. I have chosen to do what I can to pay back society for my lung transplant by promoting youth tobacco prevention globally. It does not seem fair to me that just because a youth happens to have been born elsewhere, they are not told the dangers of smoking cigarettes, how addictive the nicotine in the cigarettes is, and the health dangers associated with tobacco addiction. I created a non-profit organization called **Prevention Video Corporation (PVC)** in 1997. Those who are involved in the organization are mostly lung disease patients who have contracted their disease from smoking cigarettes. PVC has created three videos, which are designed to prevent youth smoking initiation. Over 1000 copies have been distributed in the US. The third video features addicted teen smokers describing their experiences related to smoking to younger non-smokers. Early indications show this video technique is effective and many state tobacco prevention programs are using it. PVC has also initiated a program to reward pre teens for not smoking. Youth go by Internet to the PC site, download a "statement of non-smoking behavior", sign it, and submit it for their reward. They can also submit it to PVC for a smoke free ID tag that has their name and number of years of smoke free behavior. They may also

take the statement to participating merchants who give free or reduced prices for products.

**9-29-02:** As I write these words in September of 2002, the outlook for the prevention of youth cigarette smoking globally is bleak. The tobacco companies have become partners with every international organization promoting cigarette prevention that we have located on the Internet. The prevention organizations have accepted the financial assistance of the tobacco companies because public funding is unavailable. The tobacco companies have invested in prevention organizations so they will have control over the activities of the organizations. Youths continue to initiate cigarette smoking, and become addicted to the nicotine. They are unable to quit and eventually contract any one of a variety of fatal diseases and die prematurely. I do not pretend to know at this point what action to take to break this illogical cycle of behavior but am committed to continuing to try to do so, *without* tobacco company assistance, as long as God gives me life. This article is intended to describe how we became successful at eliminating what I consider to be the biggest contradiction of our age.

**2-10-03:** Our philosophy in early 2003 has now expanded to include a smoking prevention effort, where PVC members attempt to connect teens that have a burning desire to help their peers to never start smoking, or assist those who have started to quit. We feel these teens, helping each other with a smoking issues program, will be most effective. We are pleased to be helping to hook up the teens and to letting them run with it as they see fit.

**4-9-03:** We are currently creating a 4th prevention video which is designed to not only prevent youth from starting to smoke cigarettes but also attempts to motivate youth to help their peers to also never start or quit smoking.

**Ron Peterson**

**Congratulations Ron on your determination and your hard work! We wish you great success.**

*Ron's goal is to climb all 52 14,000-foot mountains in Colorado with his transplanted lung!*

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So, is there anything new in our fight to help folks quit smoking? Yes! At the recent annual CSPR (California Society for Pulmonary Rehabilitation) in Sacramento, we heard an exciting talk by David Sachs, MD. Dr. Sachs is internationally renowned in the field of smoking cessation. He believes that *no one* should suffer from withdrawal symptoms! Would you go along with that? And how can that be accomplished? By providing pharmacological treatment for every patient trying to quit! We now feel that tobacco dependence is NOT a habit; it is a serious chronic medical disease, like asthma for instance. *It is a life-threatening illness that can require long-term medical management.*

Did you know that nicotine is the best antidepressant around? It also is a powerful cognitive function booster. What does that mean? It means if you are in a highly innovative job, such as trying to develop new computer programs, those cigarettes help keep you alert and on a sharp edge. Nicotine increases memory, decreases appetite, increases intellectual skills, increases

problem solving, decreases anxiety, increases energy and increases motivation. Wow. No *wonder* it is so hard to quit, even *without* the very addictive nature of cigarettes! That's why some people find that chomping on a 4-mg. stick of Nicorette gum can be so helpful at times of stress. Incidentally, we used to preach that Nicorette gum should not be used longer than 6 months and that it was dangerous to use it in combination with the patch. Not so, says Dr. Sachs, basing his response on careful research.

There just isn't room to go on with all the new information available. Would you like some more facts on this subject next month? Would you like to see how a doctor screens for the degree of addiction? Would you like the names of the best medications for treatment? Let us hear from you!

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### **BIG CHANGES in the Wind!**

Our Webmaster, **Dr. Janos Porszasz** has been working hard on bringing the *Second Wind* into the 21<sup>st</sup> century computer age. While you have been able to read the *Second Wind* on our website at [www.perf2ndwind.org](http://www.perf2ndwind.org) you now can be notified *immediately* when the most recent newsletter goes on line. E-mail can notify you of a new newsletter and provide a link to *instantly* access it. You have a choice of reading it on line just like any other Web page in **HTML format**, printing it out exactly as published by using the **.pdf** format, or doing both. For this, however you will need to download and install the Adobe Acrobat reader on your computer. In the notifying e-mail, you will find links to all of these, including the one to the Adobe Reader. We promise you that this is easy!

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simple as that. This will automatically enter your e-mail address in our subscriber's database. You will get a return e-mail saying that it has been received. If, for some reason, you want to stop getting the newsletter, just send a message to [unsubscribe@perf2ndwind.org](mailto:unsubscribe@perf2ndwind.org). We hope in the future to also make this a "hot line" which we can use to instantly inform you of important information. As with our mailing list, be assured that we never share any addresses with even the most worthy organizations.

*We encourage everyone with a computer to give this a try.* As you get used to this new form of communication we think you will enjoy getting the newsletter a week sooner than you would have by mail, as well as getting instant alerts on breaking news in the pulmonary field. It would also be helpful if you enclosed your name and address so that we can take it off of our mailing list. These steps will help us keep expenses down so that your donations can be directly applied to education and research.

You may also have noted that the word "*expiration*" has been added at the bottom of our newsletter labels. By next month, we hope to use this as a reminder of when we last heard from you. Subscribers who wish to continue receiving the *Second Wind* by mail need to renew their subscription on a yearly basis. While we request a donation of \$20 a year to help with expenses, we will continue to send the newsletter, without cost, to those of you who benefit by it, but are unable to afford the subscription fee. As always, our wish is to help *all* of you in the pulmonary community!

*Stay well until we meet again in May.*