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*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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**Key Words: Exercise during hot weather, Prescription costs, Oxygen Reimbursement, Newsletter renewal, CDC update on COPD**

**The Dog Days of summer are upon us.** Exercise, always an effort, becomes more so as the temperature climbs. Even at 7 a.m. the heat and humidity may be too much to face, especially when you also have fatigue and shortness of breath to contend with. So, what should you do? Give up all activity until it cools down? Tempting perhaps, but not the best idea. May we offer a few suggestions?

If you do exercise outside, try to do so early in the morning or later in

the evening. Wear sun block, a hat and sunglasses. Move slower than you usually do and be sure to drink some extra water to make up for the fluids you loose in perspiration. You live in the desert and never break a sweat? Maybe yes, but more likely not so! There is something called “*insensible perspiration*”, which is a fancy way of saying that your perspiration evaporates so quickly in the dry air that you are not aware of the fact that you are perspiring. You still need to replace lost fluids, though extra salt usually is not necessary, and can actually be

harmful when you are not training for the NFL or a marathon!

If it is really hot outside it might be better to consider some cooler alternatives.

**Malls** vary in size but all have several things in common: interesting people to look at as you walk, level areas, and **air conditioning**. They also provide bathrooms, and places to sit. Suggest meeting at the mall to another friend or two. Make it a social event. You may not be able to talk while walking, but you can socialize later over a tall glass of iced tea.

**Your local supermarket** may be closer and more practical for that daily walk that many of you strive for. An additional benefit is having a grocery cart to lean on. For those who are *very* debilitated we especially recommend this form of exercise. Leaning on a cart provides support for your body and lessens the work of exercise and breathing by supporting your arms in a raised position. You can slowly walk the aisles for 20 or 30 minutes as you pick up an item or two to take home. If you are very debilitated, stopping often to look at something won't attract attention. Grocery stores *also* offer a level area to walk, air conditioning, bathrooms, and even

a nice box boy to help you to the car should you need help.

**Swimming pools** are something that many of you have given up on. Let's face it; those of us old enough to have serious lung disease may not have the type of body seen in *Playboy*, or the energy to swim competitively. But, so what? You can still get out there and enjoy yourself. If you are afraid of sinking like a stone when you hit that water, we'll let you in on a secret. The worse your emphysema is, the more difficult it will be to sink. In fact, those of you who like to dive to the bottom of the pool may be frustrated because this is may no longer be possible. The air trapping in the lungs of those with emphysema acts like a little life preserver, helping to keep you afloat!

No one in your family has a pool? Check with your local Y, a nice safe environment. If you have a support group, try to make arrangements to reserve an outside lane for your group on a regular basis. Being on oxygen is no deterrent to swimming. Just get a 50-foot cannula, place it in the middle of outside lane, and paddle away!

**The Health Center gym at your local hospital** is worth investigating. These are preferable to the standard health clubs, which are geared to

jocks, rather than to those who are more physically limited.

**Community Colleges** often have an exercise program for those with disabilities. These are usually geared for people with a stroke or arthritis rather than for those with pulmonary disease. It might be worth a call to see if you could join one. The slower pace required for arthritis also works for those with respiratory disease. Better yet, have them call **Tom Storer, PhD** about the terrific exercise program he has for pulmonary patients at El Camino Community College in Torrance, CA. **(Phone (310) 660-3667 or e-mail [tstorer@elcamino.cc.ca.us](mailto:tstorer@elcamino.cc.ca.us) for information.)** Who knows, you may be instrumental in starting a whole new program for pulmonary patients in your area!

For those of you too far from any of the above resources there is always your own home. If you don't have an exercise bike or treadmill, you can still walk around your house. Even if you just walk during the *commercials* of a few hours of TV, you can easily get in ½ hour a day! Do you have any other suggestions you would like to pass on to our readers? We would love to hear them. ***Don't be beat by the heat!***

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### **More About Discount Drugs**

Did you find last month's information about ordering discount drugs of help? We have no interest in any of these plans, except to find something of benefit to our readers. Those plans we listed may not be the very best or the cheapest available. We encourage and welcome suggestions from you, our readers, about other sources, or about good or bad experiences, you may have had. You will be doing a service to others trying to manage this difficult problem.

**Mary** tells us she has used **Heartland Prescription Services**, a mail-order discount company, for the past year with excellent service and polite phone responses to questions. The one prescription she has to compare at this time is **Levolyl**. Ninety Levoxyl 0.05mg cost \$28.50 plus \$1.75 for shipping, or **\$30.25 total**. This works out to **\$0.336** for each pill, which was about half of the charge at a local "discount" pharmacy.

The Canadian **Dr. Solve** only charged \$10.00 for 90, *however* they charged \$20.00 for shipping and added in another \$39.00 charge a year for the physician to call, which wasn't needed. This came to \$39.95 for the 90 days or **\$0.441 for each pill**.

**Canada Drugs** charged \$17.59 for 100 plus a \$13.00 shipping fee that comes to **\$30.59** or a few cents more than the total charged by **Heartland**.

Before getting too excited about the great prices in Canada, be sure to factor in the cost of the shipping! Heartland calls before your prescription is due to expire to ask if they should mail your refill. They also will call your physician for a renewal if this is necessary. There are no age or income limitations or questions to fill out. Their address is **11028 "O" St, Omaha, NE 68137. The phone number is 1-800-228-3353.**

**Ken**, who started all of this, writes, "I just renewed a prescription for Lotensin 20 mg tablets @ **Costco**. My usual refill was for 90 tablets with a price of \$83.00+tax at Costco. I had also recently asked for, and received, a quote from Sav-on for \$110.00 for the same prescription, so Costco's price before discount was better. Understand that I have been using this drug since 1995 and had a Lifetime guaranteed price for this particular prescription from the manufacturer, Novartis, for \$60.99. Using the new **Together Rx Card**, I was limited to only a 30-day supply of 30 tablets for a total cost of \$12.00 (Cost of 90 day supply = \$36.00). This is a huge

discount of 57% on Costco's price, 67% on Savon and 41% on my Lifetime guaranteed price.

My wife, Jackie, had similar results when she renewed her 30 day supply of Monopril made by Bristol Myers Squibb using her **Together Rx card**. She also got her 30-day supply of Evista, made by Lilly, for \$12.00 when she got her Lilly Prescription Card in about a month. We figure to save more than \$100/month using the new discount cards over and above what I was already saving using my guaranteed price for Lotensin.

**Susan** writes: "I have several discount cards but the best one is from **Merck**. They request a prescription from your doctor and then send a 3-month supply of **FREE Singulair** and **Pepcid**. I got the two medicines I need delivered to my door within 2 weeks of the day that I applied for the card. You have to call for refills."

*The take home message from all of this? If you make the effort to check around you may find a way to greatly cut the cost of your prescriptions.*



### **Proposed Legislation Mandating Competitive Bidding for Oxygen**

There is some *very* important legislation coming up in Congress, which would attempt to *mandate*

**competitive bidding for oxygen.** Do you know about it? Well, read on to see what is happening in Washington. The Cape Cod COPD Support Group, led by Jo-Von Tucker, is doing their best to fight this pending competitive bidding legislation. (Jo-Von is co-author of that great book *Courage and Information for Life with Chronic Obstructive Pulmonary Disease.*) Read the letter they have sent to all of their Senators and Congressman. I hope this inspires you to also take action on this important issue. Feel free to use the following letter as a guide.

**July 20, 2002**  
**The Honorable Edward Kennedy**

**Dear Senator Kennedy:**

**Both the House and the Senate are currently considering legislation that would mandate competitive bidding for home oxygen currently provided as a Medicare benefit to approximately 800,000 Americans. We are fearful that such a move would have a seriously deleterious effect upon the availability of compact, ambulatory oxygen systems and related medical services currently provided**

**by oxygen companies.**

**Medicare payment methodology for oxygen is based upon a modality neutral model, creating strong financial pressures to provide the cheapest oxygen equipment. Unfortunately, the cheapest equipment available is invariably a stationary system such as electric concentrators or huge, heavy cylinders that supply compressed gas. These methods effectively tie the patient to a tether, or short cord, to their oxygen supply. Medical evidence is accumulating that use of lightweight ambulatory oxygen is more effective in restoring vital functions than oxygen delivered by stationary systems. Both length and quality of life is increased and hospital stays reduced by the use of these portable liquid oxygen systems. Patients such as ourselves are more able to exercise regularly and to take care of our living chores on our own like grocery shopping and doctor's appointments. Being able to get out and socialize, attend support group meetings, and to be able to spend time away from home with family members and friends helps us**

to avoid bouts of depression, which can prey on COPD patients.

**If price alone determines eligible suppliers under Medicare, there will be significant pressure to eliminate or reduce services and high quality product lines. We believe that it is bad public policy to auction off the needs of Medicare beneficiaries who suffer from a debilitating chronic illness like obstructive pulmonary disease. We are also concerned that the program would literally destroy thousands of small businesses like oxygen providers. And that it would virtually eliminate the services to COPDers of respiratory therapists and other medical professionals. We urge you to oppose legislation that would establish competitive bidding, or specifically exempt oxygen supplies, services and equipment from it. Thank you for your consideration.**

(Signatures attached.)

*For the greatest impact, this should be sent to your Senator and Congressman or woman. Please pass this information along to*

*your pulmonary physician and any one you know who is on oxygen. Let your voices be heard!*

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**PERF sends greetings and thanks to Elise Straus and her “Puffins” support group at the Providence Alaska Medical Center in Anchorage.** Mary includes her greetings to these great people and will never forget the warm welcome she received from these folks in the “Banana (Brrrr!) Belt” of Alaska.

Very special thanks also to **Tetsuji Watanabe of Kamakura City in Japan** for his continued support of PERF and the Second Wind. He says the newsletter is “Great! Super! Or, “**sugoi**” in Japanese.” We think that you are sugoi also, Tetsuji, and look forward to your next visit to the Harbor-UCLA area with your other Teijiin staff. We hope to see you sooner in Stockholm.

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Your editors Mary Burns, Drs. Rich Casaburi and Brian Tiep, as well as our Web Master Dr Janos Porszasz are all heading off Stockholm, Sweden early in September for the annual European Respiratory Society meeting. We hope to come back with lots of new information to share with you. That is, most of us will be returning. Mary will be going on to Connecticut for a few weeks, and is not due back to California until the middle of October. Much of the September newsletter is already

written but we hope to have the assistance of **Peggy Walker, BS, RT** in completing it, and the October issue.

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Dr. Rich Casaburi will also be gone since he is already on a semi-Sabbatical. Accompanied by his lovely wife he will travel on from Sweden to other pulmonary centers all over Europe, in addition to spending several weeks doing research in Holland. While we won't be seeing him again until early next year, we will stay in touch by e-mail. We may even persuade him to start a foreign correspondent column. How about it, Rich?

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***Has been more than a year since we have last heard from you?*** If so, you may have received a letter reminding you of this. We will not bother you with an annoying second notice. If we *don't* hear from you, we will assume that you are not interested in receiving the Second Wind or that you download it from our web site. We know that many hospitals, which have received the newsletter by mail, download it from our website at [www.perf2ndwind.org](http://www.perf2ndwind.org). **If you want the newsletter mailed to you, but can't afford it, we will be happy to continue sending it. BUT we *must* hear from you to know that it isn't getting tossed out with other junk mail!** If you

have any questions feel free to call us at (310) 539-8390

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### **PUBLIC HEALTH CDC Releases COPD Report**

The Centers for Disease Control and Prevention (CDC) released a report documenting a significant rise in the COPD mortality for women rising from 20.1/100,000 in 1980 to 56.7/100,000 in 2000. The authors suggest that the rise in the COPD mortality for women reflects the increase in the number of women smoking that began in the 1940s.

The report also suggests that COPD is underdiagnosed. Currently 10 million Americans report having physician-diagnosed COPD. However, CDC data suggest that 24 million adults have evidence of impaired lung function.

**CDC MMWR Surveillance Summary, August 2, 2002**

**COPD Disease Surveillance 1971-2000**

<http://www.cdc.gov/mmwr/PDF/ss/ss5106.pdf>  
(This requires free Adobe reader with address below if you don't have it  
<http://www.adobe.com/products/acrobat/readstep2.html>)

*That is the bad news. The good news is that there is an increased awareness of this disease and the need for research and new treatments. Keep reading the Second Wind for the latest information. Until next month, stay well!* ☺☺☺