



# Second Wind

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## NEWSLETTER

**SEPTEMBER 2002**

*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: Flu season, Oxygen legislation, Preparing for an office visit, Questions for shortness of breath (SOB)

**Flu season is coming!** It is time to make an appointment with your physician or to watch your local news to see when the free clinics will be offered in October.

Thanks to all of you who renewed your subscription and added those nice comments. We like feedback and we *especially* like nice feedback! Several of you have suggested that we put expiration dates on the labels. Great idea. We have been trying to find someone who can help us figure out how to do it. Obviously, we are not going back to the “expert” that messed

up our database. We are *still* correcting some of the errors we discovered, and we thank the patience of those of you who had your contribution dates erroneously reported.

We all owe special thanks to **Merritt Marks of Pennsylvania** who enclosed a very generous donation with his renewal. It is the generosity of folks like Merritt that allow us to continue sending the newsletter to those of you who can't afford it. Remember, all we need from you is an acknowledgement that you

wish to continue receiving the newsletter. We will be delighted to continue to send it to those who find it helpful.



Do you golf? **Jim Barnett, RRT** of Mission Community Hospital in Mission Viejo, CA goes golfing with one of his patients who, even on 6 liters of oxygen per minute, desaturates with activity. How do they manage a game of golf? When they pay for green fees, his patient requests a handicapped flag for the golf cart. With the flag flying on the golf cart, this patient rolls along *anywhere* except on the greens. *The moral of this story?* Don't let being on oxygen keep you from enjoying life!

Do you also have a success story to share with us? Send it in to help us inspire others out there and remind them that: Yes, you *can* enjoy life with respiratory disease!

And speaking of Jim, we think the letter he sent to his patient club about the legislation in Congress on competitive bidding for oxygen is worth reprinting.

*This month I am writing to you to let you know what is happening in Congress. The Senate is 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 major effect upon the availability of certain types of oxygen systems to Medicare beneficiaries.*

*If this competitive bidding legislation is approved, it would cause strong financial pressure to provide the cheapest oxygen equipment available. Unfortunately, the cheapest equipment available is invariably a stationary system such as an electric concentrator or a heavy cylinder that supplies compressed gas. This could significantly decrease the ability to be independent and to be more mobile. This could definitely limit your choice for certain lightweight conserving devices. As we know, the 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 lightweight portable systems when it helps you stay more physically active.*

*If price alone determines eligible suppliers under Medicare, there will be significant pressure to eliminate or reduce services and high quality product lines. I am very concerned that if this legislation is approved it would literally destroy thousands of small businesses, like oxygen providers and eliminate research for new lighter weight oxygen devices. It also would virtually eliminate the services to COPD patients from respiratory therapists and other medical professionals.*

*Ongoing service, and the support of DME companies, are an integral part of helping the patient have a better quality of life. What keeps service levels high is competition between the many companies in any given geographical area. Passage of competitive bidding would eliminate many providers from the Medicare oxygen pool. Once this happens, the competitive pressure lessens and a deterioration of the level of service is sure to follow. Access to quality home care would be severely limited based upon price bidding alone, with no service or choice issues even considered by the powers that be.*

*I urge all of you to respond by sending letters to you congressman, senators and any other representative of our government.*

Jim went on to supply the names and addresses of the Congressman and Senators representing his area. May we suggest that instead of mailing letters you send them by fax or e-mail? Since the anthrax scare, letters take a long time to go through the precautions now installed. A fax or e-mail is received with greater enthusiasm. We know we covered this issue last month but it is so important that we felt it worth repeating.



### **We Get Mail**

*Ginger writes* that it has been more than 10 years since she has seen a doctor. Even though she quit smoking a year ago, she has been feeling short of breath lately. Reluctantly, and rather nervously, she has made an appointment with a physician. She wonders if we can tell her what to expect, or if we have any suggestions that will make it a little easier to face that physical?

We'll try! First of all, congratulations on taking charge and doing something about your symptoms. You've already accomplished the most difficult part of that upcoming physical. You've gone a year without smoking! Will you feel better if we reassure you that by making that appointment you also are past the second hurdle? Now lets

see if we can give you a few tips to help you make the most of this visit as well as others you will have in the future.

One of the first mistakes people often make is to minimize their symptoms or even ignore them. No one likes to be thought of as being a complainer, or heaven *forbid*, a hypochondriac! How many of you have answered, “Just fine.” when asked how you were feeling? If you were “just fine”, you wouldn’t be in the office! If a plumber comes to your house, do you make him guess what the problem is, or do you have some specific complaints for him to work on? You give him all the information you have, right? Do the same favor for your doctor! He has many years of training but is not too good with a crystal ball or playing 20 questions!



Organize your visit by preparing a list of all the medications you take, the dose of each, and the times of day that you take them. This includes over the counter meds and even eye drops. If this is too difficult for you, dump them all in a paper bag (or suitcase) and just bring them along.

Next, think carefully about what your problems are, and how they concern you. List them on a piece of paper starting with the most serious symptom first. It may be difficult to cover more than 3 big problems in your allotted time. If you have many more, it might be good to warn the staff in advance and see if you can get a double appointment.

When you first go into the office, you may need to fill out an extensive questionnaire about your medical history. They may even send the questionnaire to you in advance. You will be asked for dates about things like surgeries or major illnesses, along with a smoking history and recent weight gain or loss. You also should have the date of your last booster shots, especially tetanus and pneumonia. The staff will measure your height and weight, and check your blood pressure before you see the physician.

Getting down to shortness of breath (SOB) specifically, there are many things that can cause an increase in SOB besides pulmonary problems. Possibilities to rule out include things like heart disease, anemia, thyroid disease as well as the obvious ones of anxiety, obesity and couch potato syndrome. Since it has been many

years since your last physical, the physician may order:

- Complete panel of **fasting** blood work to rule out thyroid disease and anemia as well as the usual check of cholesterol levels, etc. This means that you shouldn't eat anything for at least 12 hours, though you can have that morning cup of coffee if it isn't loaded with 3 teaspoons of sugar and 2T of half and half.

- A chest x-ray
- EKG



As someone with a heavy smoking history and SOB you may also have:

- Full spirometry (with a flow loop). This is a simple breathing test done in the office to see if there is a decrease in lung function. A decrease can be temporary, as during an asthmatic flair-up or pulmonary infection, or more permanent because of emphysema or chronic bronchitis, or restrictive disease. If very abnormal, it may later be followed up with a full pulmonary function test (PFT).
- A 6-minute walk with an oximeter to see if your

oxygen level drops with activity.

- Pneumonia shot in addition to the annual flu shot, usually given around October. Anyone over 65 should have these preventative measures, even without a smoking history.

Since it has been more than a year since your last physical, as a woman you will get:

- A pap smear
- A mammogram
- A check for occult blood in your stool (everyone)

Ask about

- a bone scan (densitometry)
- tetanus booster, if it has been 10 years since your last one.

If this sounds like a lot, it is!  
About 10 years worth squeezed into one visit!

Since your most annoying symptom is shortness of breath, think through some of the following questions that the physician *might* ask. If you have answers, it will help a great deal in coming to the correct diagnosis and getting the help that you need.

- How far can you walk on a usual day before getting short of breath?

- When did you first notice the shortness of breath (SOB)?
- What were you doing at the time?
- How often does it occur?
- What are you doing when you notice it?
- On a scale of 1 to 10, 10 being the worst, how would you rate it?
- Has it gotten worse lately? If so, give an example such as, “I used to be able to walk 4 blocks with out difficulty. The past 2 weeks I get short of breath walking across the room.”
- Does it wake you up at night? At what time?
- How many pillows do you need to sleep?



- Have you noticed irregular heartbeats, a fluttering feeling in your chest, or rapid heartbeats?
- Have you gained, or lost, much weight recently, and if so, how much?
- Do your feet swell? If so, when and how much? Are they swollen all of the time or only after you have been standing?
- Do you have any pain associated with your SOB? Where is the pain?

- How much salt do you have in your diet? Have you noticed that it affects the swelling of your feet?
- Do you ever hear yourself wheezing?
- Do you cough? How often and when, e.g. only at night?
- Is your cough productive of sputum?
- If so, how much sputum do you bring up, a teaspoon, tablespoon or cup every day?
- How thick or thin is it?
- What color is it? White, creamy, yellow, streaked with yellow, green or blood tinged?
- Has there been a recent increase in sputum or recent change in the color?
- Have you coughed up any blood, vomited blood, noticed blood in your stool, or had any black tarry stools?
- Have you had any *recent* weight changes or feeling of weakness?
- Have you been under excessive stress lately?

Will the doctor ask you all of the above questions? No, but he *will* be considering them, and so should you. Are you overwhelmed by all of these questions that run through the mind of your doctor? Be *pleased*, instead, that all possible causes of your SOB are being considered.

Think about the questions above before going in for your appointment. Don't be afraid to admit that you have a problem. That is the only way you are going to be able to take care of it! Give the significant answers to your physician or be prepared for some of these questions.



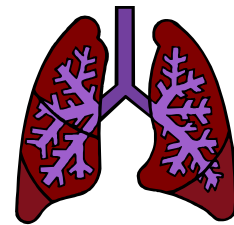
Write down answers, or questions, that you are afraid you might forget. Bring someone with you if you are nervous about going alone or forgetting what is said. Request a copy of all of your tests.

Congratulations on following through with your appointment, good luck, and *most* important, bring a book! It can be a long wait in that office!

**Sandy writes:** I just you're your article entitled "The Importance of Proper Breathing Techniques". I have a particular symptom with my breathing. I will be breathing normally, and then it is as if my lungs all of a sudden fill with air, as if I were doing a deep breathing exercise. What is strange is that it is involuntary on my part. It feels as if my lungs are filling themselves with air quickly and all of a sudden. It does not hurt, but just startles me. Do you know what this could be? I would

appreciate anything you would like to share with me. Thank you so much.

Dear Sandy,  
If you never took a deep breath, some areas of your lungs would not expand properly and could collapse. A periodic deep "sigh" is normal and helps keep your alveoli (little air sacs) open. Usually this is done without even being aware of it. You might be particularly sensitive to the sensation associated with this need to "sigh" periodically.



The respiratory system is unique in that we do have some control over a system that becomes automatic while we sleep or when we are unconscious. As you know, when people become very nervous they sometimes take a deep breath. Or they may hyperventilate (breathe too fast) to the extent that they can even faint. At that point, their respiratory system becomes automatic, they breathe normally, and wake up again. Watching your breathing patterns may give you a clue as to what is going on. You are with yourself 24 hours a day while the doctor only sees you for 15 minutes or even less. The more information that you can provide,

the easier it is for your physician to diagnose what is going on. There is no way that we can give you an accurate diagnosis by e-mail so you should, of course, discuss this With your physician. Good luck and let us know what he has to say.

Don't miss the information filled October issue of the Second Wind. Rich Casaburi, Janos Porszasz, Brian Tiep and Mary Burns will all be back from Sweden. They are now at the European Respiratory Society Annual Congress in Stockholm where they are attending (*and* presenting) sessions on what is new in pulmonary rehabilitation and COPD. The group will also be at Upsala University for several days where they will happily join again with Margareta Emtner, PT, PHD and



her colleagues. While they will present some sessions on pulmonary rehab and care of the COPD patient in America, they hope to exchange ideas with their Swedish counterparts. It should be a learning experience for all. They look forward to it and we hope it will benefit all of you also, when we present the highlights next month.



Until then, stay well, keep exercising and don't forget to schedule that flu shot!