



# Second Wind

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## NEWSLETTER

**November 2005**

***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.***

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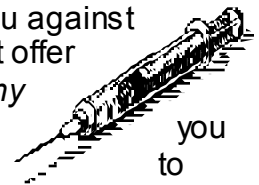
Bird flu, Disaster preparedness, 6<sup>th</sup> Oxygen Consensus Conference, COPD Day in Hungary, Hypnosis, Asthma cigarettes, Oxy-view glasses, Dr. Petty's book, Nonin Onyx, Cruise, In-X, CSPR conference

*We wish you and yours a very happy, healthy  
Thanksgiving!*



**Have you heard of Avian or Bird Flu?** Do you find yourself looking up at every flock of birds flying overhead and shudder with memories of Alfred

Hitchcock? To get the straight scoop, go to the end of this newsletter and read what Dr. Tom has to say. We know that anyone smart enough to subscribe to this newsletter will already have gotten their flu shot for this year, since the old fashioned flu right now is a greater *immediate* threat to those with pulmonary disease than is the *potential* threat of bird flu. But, just in case you haven't yet gotten around to it, call your doctor right now for an ASAP appointment! A word of warning. Flu shots do *not* protect you against all flu. And they do not offer total protection from *any* flu. However, even if you are unlucky enough to come down with the flu, despite having



gotten a protective shot, it should be a milder case rather than that life threatening disease that causes so many deaths each year. And just to be on the safe side, carry around a bottle of hand sanitizers, or handy wipes, and follow the all the other suggestions of Dr. Tom.

**We, and all of our readers, offer our sympathies,** condolences and best wishes to those of you who were involved in either of the hurricanes that devastated the Southeastern United States and the Gulf



Coast. If you have any stories of how you managed to overcome some of the problems you had to deal with we would like to share them with other readers.

**Oxygen concentrators and loss of power** Many of our patients on oxygen concentrators have expressed concern, and fear, about the effect a loss of power might have on them. There have been stories, exaggerated by the newspapers, suggesting that patients on concentrators or oxygen are in serious danger. Some articles even suggested heading for the nearest fire station or hospital in the event of a black out. *Not necessary, folks and your local fire department begs you not to even consider it!*

Even if you don't have a back-up tank of oxygen just about every one of you, unless you are on a ventilator and totally unable to breathe, can get by for *much, much* longer than you realize without supplemental oxygen.

**Ventilator patients** are a different matter, but *by law* these patients always have stand-by emergency equipment in case of a power failure. These patients should also notify local police and fire departments that they are on a ventilator. Their oxygen company also should put them first on the list of patients to help immediately. But again, *this is not considered necessary for those on oxygen concentrators.*

Craig Murga, RRT, a Manager of Lincare, gave us some other disaster tips for the Second Wind back in 2002 that deserve repeating.

#### **Gas Generators:**

Some patients have purchased gas-powered generators to alleviate their anxiety. In many parts of the country it is an annual event to experience long-term power interruptions because of blizzards, electrical storms, or flooding. The recent hurricanes have made all of us aware of the need to prepare for a natural disaster.

Gas-powered generators are wonderful when it comes to running a light bulb. But, because of the low output on most generators, typically they are insufficient to run a concentrator. Also, generators tend to constantly cycle, causing concentrators to blow fuses. So, if you're going to use a generator to run a concentrator, make sure it works, and find out where the reset button is located on the concentrator.

Then there's the problem of storing gasoline for the generator. How much gas do you store? Can you store it in a safe location away from any heat

source? How often do you rotate your supply? Gasoline *does* go bad!

### **Financial Help**

Do all of you who use concentrators know that by contacting your local electrical company you will get a rate reduction in your electricity costs? This is true for all electrically driven medical equipment including nebulizers and electrical beds. If you live in a hot climate and your doctor feels you need air conditioning, even that may be eligible for a refund. If you have not done so already, call today and request information about the Medical Baseline form. This may have a different name in different parts of the country, but all electrical companies should have a similar program.

**If you are on a concentrator** you can help yourself by always maintaining a sufficient stock of cylinder gas to see you through an extended power failure. If you use 2 LPM (liters per minute), three E-cylinders will give you about 18 hours of oxygen. By reducing the oxygen flow to 1 LPM you will get approximately 25 hours of oxygen usage. If you think you might be without oxygen replacements longer than that, try turning the flow down to ½ lpm or even turning it off when you are at rest. If you have an oximeter you can titrate your oxygen, not using it unless you go below 89% or 88% saturation.

You may have forgotten this, but I'll bet many of you probably qualified for oxygen many months before you started using it. Remember this, and more

importantly remember that you not only survived, but you probably resisted using oxygen when it was first prescribed for you! Don't panic and you will probably be fine until you get your oxygen supply again. **Remember, most oxygen users can go without oxygen for moderate periods of time without suffering major debilitating effects.**

### **PLB**

Also remember that, properly done, in some people pursed lip breathing can bring your oxygen level as high as 2 lpm of oxygen can. This is the time to learn good breathing techniques, if you have not already done so. (If you have an oximeter, try using it to improve your breathing techniques by monitoring your improved oxygen saturations.)

Confidence in your breathing techniques will help you prevent panic.

### **Disaster Plan**

Have you planed on an alternative location to which you could relocate in the event of a disaster? Notify your oxygen supplier *in advance* of this other location so that they can find you if the occasion arises. All oxygen suppliers should have a disaster plan policy in place to prepare for the inevitable. If you are unaware of your company's policy ask them to send you a written copy.

Take a few moments to prepare a disaster kit to be kept in a safe area.

- Include a particle mask if you are prone to bronchospasm from dust.
- Have an extra inhaler and medications in the kit. When you store medications be aware of the expiration dates on your meds since

you will need to rotate them on a regular basis.

- You should also have a portable radio with long life batteries stored separately to help you find relocation centers if necessary. A radio also helps you connect with the rest of your community, which reduces the level of stress, one of the most important things you can do for yourself.
- Don't forget a few bottles of water and some easy to eat food.

You can find more information on disaster preparedness by checking the front pages of your phone book, contacting your city hall, or checking with your local chapter of the American Red Cross or American Lung Association as well as your oxygen provider.



### **The 6<sup>th</sup> Oxygen Consensus Conference**

this August in Denver, Colorado was a three-day marathon of meetings and sometimes heated discussions about oxygen for our patients. Represented at this conference of 100 invited participants were scientists, HMO executives, patients, manufacturers of oxygen equipment, NIH, oxygen suppliers, health care providers and 3<sup>rd</sup> party payers from Medicare and insurance companies, along with observers from Europe and Japan. In other words, quite a mix. Three members of the PERF Board attended: Rich Casaburi, Brian Tiep and myself while the meeting was Chaired by Dr. Tom Petty. The four of us all presented lectures. As you can imagine, there were many different outlooks on what the problems are and how to handle them. None of us will completely get what

we want for our interest group but all of us came away with a better understanding of the problems faced by groups other than our own. The leaders of the discussion groups have written up the important points decided on by individual groups and this is now being written for publication next January. We will keep you posted and print a summary as soon as it is available.



This is late notice, but **World COPD Day** will be celebrated in this country on Wednesday, November 16<sup>th</sup> around the theme "Breathless not Helpless!" The website [www.goldcopd.com](http://www.goldcopd.com) has information and ideas on what to do. The Great American Smokeout is also on November 16<sup>th</sup>.



### **Do you ever listen to the Hungarian National Radio through the Internet?**

You don't? Well if you did you would hear a periodic announcement that "*The Hungarian Pulmonological Society*" has declared November 17th to be National COPD day. Organized pulmonary function screenings will be offered to the public. The first 150 people who sign up will receive free complete pulmonary function tests." Who is responsible for this progressive move in an Eastern European nation? While he remains modest, there is no doubt in our minds that our friend **Dr. Attila Somfay** played a major role. Attila is a member of Presidency (Board of directors) of the 11 member Hungarian Respiratory Society Gremium. One year ago, they declared 2005 "the year of COPD". Here is his description of recent activities.

*We organized lot of nationwide activities on this topic. The broadcasted commercial was a piece of this activity. I personally played major role in this program. Among others, I put together a slide presentation for the diagnosis of COPD, which was presented at 30 different places in the country. I wrote a book for COPD patient (with your major support, thanks to Tom Petty as well), which will be introduced to the public on 19 November, when we deliver several presentations in a daylong symposium on COPD. This will be the closing event of the year of COPD.*

*On 17 November, the day of COPD, there will be free spirometric screenings for the public in Szeged (200,000 people) and Hódmezővásárhely (60,000 people) at pulmonary clinics. In the near future, according to my suggestion, we will try to organize nationwide spirometric screenings for smokers (or previous smokers) between the ages of 40-70 years. This is the major source of COPD. Thanks again for supporting us."*

Why are we telling you all of this? Attila spent a year and a half at LA Biomed, Harbor-UCLA doing the required research for his PhD with Rich Casaburi and Janos Porszasz while also learning about the benefits of pulmonary rehabilitation. He went back to Hungary and convinced a skeptical community, as well as many physicians, of the value of smoking cessation programs, early screening for pulmonary disease, and pulmonary rehab in this country of heavy smokers. (We could use his help here!) Attila remains a wonderful example of how the training of just *one* physician can have a major impact

since, in addition to starting pulmonary rehab in Hungary, he is promoting it in other Eastern European countries. Funding to train physicians such as Attila Somfay is one of the missions of PERF. We have already started such a fund dedicated to this very worthwhile purpose. Perhaps Dr. Rich Casaburi will tell you more about it in his annual appeal for financial help.

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### **We Get Mail**

Alice would like to know if hypnosis will help her get off of oxygen.

Hypnosis sometimes has its place, especially when dealing with emotions. For instance, if you were very short of breath and thought you needed oxygen when your tests showed you were in the normal range, hypnosis might be helpful in overcoming your anxiety and fear of not having enough oxygen. Pulmonary rehabilitation, however, can *also* do this along with teaching you many other things. We think it is a better long-term solution. Oxygen need is not based on subjective feelings of shortness of breath. It is based on defined levels of the partial pressure of oxygen in the arterial blood gas, or of oxygen saturation as shown on an oximeter. That is, your tests must show that you desaturated to 88% or less or that your PO<sub>2</sub> was 55 or less in order for you to be eligible for an oxygen prescription.

There are times when you are put on oxygen with a saturation of 89% or a PO2 of 60 or less but these are carefully defined. These numbers are not influenced by your attitude or positive thinking. They *can* be influenced by pulmonary infections, proper, or improper, use of respiratory medications, and breathing patterns. If you have recently had a marked increase in shortness of breath you need to call your pulmonologist to see what is going on. If all the possible problems, as mentioned above, can be ruled out, we'd suggest a pulmonary rehab program for lasting benefit.

Lowell writes:

When I was a kid, long, long, long ago, I remember a cigarette called 'Blosser' being sold as a medicated cigarette. This is just a curiosity that I have been unable to chase down. Do you know about it?



*Recently (2 1/2 weeks) I started taking Tiotropium bromide inhalation powder. Is this related to any of the old fashioned remedies? I thank you for your articles - I find them very interesting (and yes even somewhat comforting).*

Thanks, Lowell! Blossers were "asthma cigarettes" sold in the early-mid 20th Century. The medication (often stramonium or belladonna) is actually distantly related to tiotropium. The cigarettes were acid and must have been difficult to smoke, but

were said to have produced bronchodilation. Hope this helps.

And by many readers we were asked, "Where can I learn more about Oxy-View eye glasses or order them?"

Oxy-View TM eyeglass frames, fitted with your prescription lenses, will combine corrected vision and oxygen therapy, up to 5 liters per minute. Check their website at

[www.oxyview.com](http://www.oxyview.com) or telephone 877-699-8439 for information.



Mary sends special thanks to Kevin and Judy Hettich for their generous donation to the Chair of Rehabilitative Sciences in the name of Mary Burns



**Some Christmas Gift Suggestions!**



**Frontline Advice for COPD Patients, by James T. Good and Thomas L. Petty** is now in second printing. The first issue of 100 thousand was exhausted, but it still remains in high demand. This 125-page book, written in language that all patients can understand, is available on line from [www.xibris.com](http://www.xibris.com) for \$17.84 for a paperback and \$27.89 for the hard cover edition. At [www.amazon.com](http://www.amazon.com) you have your choice of new or slightly used





books starting at \$15.73 as of this writing.

### **The Nonin Onyx 9500 Pulse Oximeter**

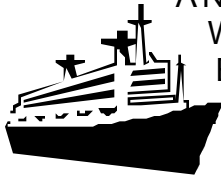
can be ordered from [www.portableneb.com](http://www.portableneb.com) for \$264.95 with free delivery and a 2-year warrantee. Call 1.888.225.2509 for information.



This is the oximeter used in many hospitals and doctors' offices. In addition to tracking your oxygen saturation you may find it a good biofeedback device for monitoring your breathing techniques.

### **Cruise**

Looking for something more luxurious? A Neiman Marcus type of gift?



Well, consider this. Jim Barnett, RRT still has some cabins available for his 10-day **Inland Passage Cruise to Alaska** for those with

pulmonary problems. He already has about 40 of his patients signed up but there is lots of room left if you want to join this fun loving, sociable and friendly group. They are sailing from San Francisco on The Regal Princess, June 15<sup>th</sup>, 2006. Call Jim at 1.877.280.2777 for further information.



### **What is coming up next year?**

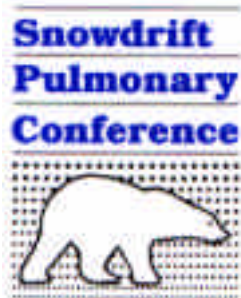
**Have you heard of the In-X?** Dr. Petty tells us that its system involves any 5 lpm or greater ordinary concentrator that diverts one liter per minute of oxygen flow to a cryocooler. The cryocooler



uses the principle of heat of compression. This heat is dissipated so that the contents are cooled. *Liquid oxygen is therefore produced in the home!* You can fill ANY liquid system with it. It can provide continuous flow of 0.05 to 3 lpm even while trans-filling and it can transfill three In-X strollers a day, thus providing up to 16 hours of mobility. In-X is in the process of selling to a major, well-known company for wide distribution. This could eliminate home deliveries and revolutionize LTOT. It is a real breakthrough, though not yet perfect. Other alternative methods of making liquid oxygen in the home are also under development. This is some pretty exciting stuff, folks, so stay tuned for further developments!

### **Next May 18 to 19, 2006, CSPR**

**(California Society of Pulmonary Rehabilitation) will hold its annual conference in San Diego**, two days before ATS. If you are a health care professional save this date and make plans now. These two days will be crammed with information on what is new in pulmonary rehab. Some of internationally renowned guest speakers already confirmed will include Richard Casaburi, PhD, MD, Brian Tiep, MD, Barry Make, MD, Francois Maltais MD, Thierry Troosters, MD and Attila Somfay, MD, PhD. This exciting conference will only be \$185 for *both* days! Our reserved rooms are only \$130 a night. Budget for it now and plan to come to beautiful San Diego to network with other health care professionals dedicated to pulmonary rehab!



The Snowdrift  
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Senior Moderator

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November, 2005

## Clues About the "Flu(s)"

Dear Friends:

Every fall we worry about flu epidemics that may be coming. The true "flu" is influenza, a viral infection of the lungs. It can cause severe bronchitis and even pneumonia. It is often complicated by a later bacterial pneumonia, too. Flu epidemics are in the "A" family of viruses. "B" strains are also present, but they usually do not cause epidemics. Most influenza originates in Asia. Thus we have the "Hong Kong Flu", the "Chinese Flu", the "Australian Flu", etc. "A" type influenza viruses contain antigen markers labeled "H" and "N." The N is for neuroamidase, an enzyme necessary for the pathogenesis of influenza. These N antigens mutate most years. This is why last year's vaccine will usually not protect against a new mutant this year.

Influenza vaccine contains a complex of H and N antigens. This year we are particularly afraid of the "bird flu", which is designated H5N1. We don't have a vaccine for this one yet, and we hope that it does not cause an epidemic! This would be disastrous. Last year the Asian flu vaccine was in short supply because of manufacturing problems. This is being addressed this year and more vaccine will be available. The vaccine is also effective against B strains of influenza. But vaccination is only about 80% effective, and it tends to fail in older people and those with poor immune defenses.

There are also antiviral drugs that can prevent, or treat influenza if used when it just starts. Older drugs such as amantadine, and rimantadine, are not as effective as the new Tamiflu, and Relenza. Relenza is an inhaled drug and not good for asthmatics or those with COPD because of the irritation it causes. Tamiflu is a very good oral drug, and it may be a lifesaver if we get the bird flu, and in people who are not protected from any vaccine that is



available. Tamiflu should be on hand for all at high risk, i.e., older people and babies, and those with severe organ system diseases such as heart, lung, kidney, liver or diabetes.

**Influenza causes a well-recognized set of symptoms and signs. A sudden cough, fever, and severe muscle aches and pains are the tip off.** If this happens suddenly, Tamiflu, two tablets a day, will usually abort the disease. It can be lifesaving. Tamiflu can also be used for prevention at one tablet a day, but it is probably best reserved for influenza when symptoms **FIRST START!**

Many other illness are called the "flu," such as the "stomach flu", the "24 hour flu", and so on. This is NOT influenza and should *not* be treated with Tamiflu. Also, the common cold is not treated or prevented by Tamiflu. Tamiflu should be kept in reserve for the true influenza.

If an epidemic hits, avoid crowds. Wash your hands frequently and take packaged hand wipes with you that contain a disinfectant. Be distant, even from your friends. Avoid kissing and hand shaking during a flu season. Just wave and smile. Influenza is a serious disease and we must be sensible about dealing with it. Keep healthy!

I'll be in touch next month.

Your Friend,

A handwritten signature in black ink, appearing to read 'Tom' or 'T. Petty', written in a cursive style.

Thomas L. Petty, M.D.

*Professor of Medicine, UCHSC*

*President, Snowdrift Pulmonary Conference*