



Second Wind

NEWSLETTER

JUNE 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.

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New BOD changes Dr. Petty, & Jim Barnett, RRT, Mark Junge, bicyclist; Norway, Russia, Hungry, Herbs Part 4, End of Life, Panic Attacks, Search tool;

Have you noticed any changes in our PERF Board of Directors? **Dr. Tom Petty** has gone to "the top of the list" with the title **President Emeritus**. Tom feels unable to continue to actively participate in Board meetings but, with this title, will always be able to officially offer us his valuable advice. And we got more good news about our friend. He has successfully gone through his 4th (and *last* we hope!), open heart surgery. He is doing fine but still a long way from full recovery. He asks that you continue with your wonderful thoughts and prayers which he feels have really helped him. He's not ready for phone calls but will welcome cards, which can be sent to

899 Logan St., Suite 203, Denver, CO 80203. No

flowers please! If you would like to honor him in this manner, it is suggested that you plant something you really will enjoy in your own yard or patio. His thanks again to everyone.



Dr. Thomas L. Petty



Jim Barnett

We are delighted that **Jim Barnett, RRT, RCP** has agreed to join the PERF Board of Directors. Jim is one of the leaders in his field being very active in **AACVPR (American Association of Cardiovascular and Pulmonary Rehabilitation) as well as CSPR, the California Society of Pulmonary Rehabilitation**. He has been past president of CSPR for 5 terms! Jim has been Coordinator of the pulmonary rehab programs at **Mission Hospital in Mission Viejo, CA** for the past 16 busy years having graduated almost 800 patients in 105 classes! Almost as important is a great maintenance program that Jim



Mark Junge

oversees along with an active, popular support group, second to *none*. We'll tell you more about them next month when we attend the 16th Birthday celebration of this great group. Jim's wealth of experience, and well known dedication to his pulmonary patients, make him a wonderful addition to our Board. We are so pleased that he is joining us! Welcome aboard, Jim!

61-YEAR-OLD OXYGEN-DEPENDENT CYCLIST EMBARKS ON CROSS-COUNTRY TREK, MOTIVATING SENIORS TO STAY ACTIVE

Does that headline catch your eye? It did ours. On June 12, 2004, sixty-one-year-old **Mark Junge from Cheyenne, Wyoming** saddled his bicycle and began his 3,400-mile trek from San Francisco to New York City. Mr. Junge is not your typical cyclist attempting the mid-summer trip across the grueling and often mountainous Lincoln Highway. He is a 61-year-old retired historian and photographer from Cheyenne, Wyoming. Most interesting to us however, he is also on 24-hour oxygen.

In the winter of 2002, blood clots developed in Mark's lungs. Because the problem was atypical, its cause was not immediately recognized. As a result, the clots caused permanent damage that reduced his lung capacity, requiring him to use oxygen for sleeping, walking and exercising.

Having dedicated his professional career to preserving history, Mr. Junge is now planning to make his own, by being the first man requiring liquid oxygen to cross the United States by bicycle. His wife, Ardath, will play a key role during this three-month

odyssey by driving Mark's support vehicle and providing logistical assistance.

He will be using a HELiOS liquid oxygen system as his constant companion. This portable system is only 10 inches tall, weighing 3.6 pounds when filled and can last up to 10 hours, making this trip possible.

Mark says that the trip is not only a personal goal, but also an opportunity to demonstrate to other oxygen-dependent individuals that they, too, can stay active and independent. From San Francisco, Mark will travel the historic Lincoln Highway, which runs through America's heartland. The Lincoln Highway, conceived in 1913, was the first trans-continental road built specifically for the automobile. He began his ride at the western-most point of the highway, San Francisco's Legion of Honor in Lincoln Park. He will culminate his journey at the route's eastern terminus, Times Square in New York City. Along the way, Mark hopes to meet with federal legislators in their home districts in an effort to educate them on the issues preventing many oxygen-dependent Americans from getting the *small, lightweight* portable delivery systems that allow them to maintain active lifestyles.

Medicare and most insurance plans cover portable liquid oxygen systems when medically indicated and prescribed by a physician. However, government payment for lightweight liquid oxygen systems is no more than that for drag-behind-you E-cylinders. The challenge is educating more physicians, patients and legislators to demand lightweight systems. We hope that Mark's trip across the country will help raise awareness of the need for small portable oxygen systems so that more

oxygen dependent patients can benefit from them. To follow his progress go to www.heliosfuturenews.com. We'll keep you posted on his progress, and join all of you in wishing him a successful journey. You have our greatest admiration, Mark!

NEWS FROM RUSSIA AND NORWAY

Dr. Audhild Hjalmarsen emails that she just returned from an excellent pulmonary conference in Moscow with 70 Norwegian and 200 Russian pulmonologists. **Dr. Olga Baranova** is planning to start a pulmonary rehab program for her sarcoidosis patients in **St. Petersburg**. She has a colleague, Dr. Irina Saremba, who is working with their COPD patients and now has 10 patients receiving LTOT (long term oxygen therapy), thanks to the oxygen concentrators they have gotten from Norway. Another young physician from St. Petersburg was very interested in smoking cessation and had lots of question for **Dr. David Sachs of Palo Alto** who gave a day of his time to this group informing them about the important topic of smoking cessation.

Dr. Elmira Zilber is working hard to create her own model of a pulmonary rehab program that suits the circumstances in **Karelia, Russia**. They have received money from Norway to spend on this project. The Polarmed Ltd. Company has donated another 5 used oxygen concentrators that Audhild will bring the next time she goes to Russia in October.

Back in **Tromso**, **Dr. Hjalmarsen** is involved in several research studies involving their maintenance program, including one on nicotine

replacement/bupropion for their heavy smokers.

Wow! Are we impressed! Once these dedicated doctors get an idea they go full steam ahead. The progress made in Russia in such a short time is truly amazing. We congratulate all of them and wish them the greatest continued success.

AND FROM HUNGARY

More good news! Dr. Attila Somfay emails that he is giving a report to their National Congress on Pulmonology on his early efforts to promote nationwide spirometry aiming at early screening for COPD. He wants to give credit to **Dr. Tom Petty** for promoting this. He also attended the 6th Finnish-Estonian-Hungarian Conference of Pulmonology in Helsinki, Finland where he lectured on pulmonary rehab in Hungary. He mentioned the collaboration with Harbor-UCLA and our visit to Deszk, Hungary last September. He also showed pictures of the **Nonin oximeter** we gave him last September being used in their pulmonary rehab. **(Thanks again to the Nonin Company for their donation that made this possible!)** Attila is justifiably proud of the rehab program he now has, which is based on his experience doing research here at Harbor-UCLA. He said that the Finns have started a program, but it is only 2 weeks long.

We are so pleased to share with you the progress that has been made in the early detection COPD, and patient rehabilitation, thanks to the efforts of our good friend, Attila. It is inspiring to work with yet another dedicated physician, and to know that this help

for COPD is now becoming global. It is wonderful to be involved in international cooperation with people of good will, in programs that are really helping people. Isn't it nice to hear some good world news for a change?

HERB on HERBALS

PART 4 of 5 parts

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.

Herb on Herbals continues with part 4.

Let me start by saying that I am definitely not an expert on herbals. My perspective is that of a skeptical, professional, conservative, mainstream pulmonary physician, and my watchwords are "Prove to me that it is safe and effective before I put it into my body, or recommend it for you." I approach this task hoping to accommodate an attitude that herbals are *complimentary* rather than an *alternative* to conventional medications. Over the past months, I've written about logically examining herbal supplementation.

"Don't you have ANYTHING good to say about natural products?" Yes, of course, I do. Remember, my view is

from a scientific standpoint, and although you can find many people who will tell you *subjectively* that taking herb X does wonders for them, I'm discussing *objective* evaluation. So here are some good examples of positive study results that will be of interest.

First, for decades, Grandma has said that **cranberry juice will prevent urinary tract infections**. This is especially important for a large percent of women over the age of 65 since this group statistically gets about one urinary tract infection a year. Not only was this proven to be true in elderly women in a well-done randomized, double blind placebo-controlled trial, but in addition, we know the mechanism of how it works! It really has a scientific basis now. Although it was previously thought that cranberry juice acidified the urine, hence improving bacterial clearance, it's now known that in fact specific compounds in cranberry and blueberry juice inhibit the adhesion of bacteria to the bladder wall. *Just cranberry and blueberry juices, not other fruit juices*. And you can even get this benefit from the low calorie version of Ocean Spray Cranberry Juice cocktail. I recommend this for anyone with recurrent urinary tract infections and for women over the age of 65.

Here's another good story. Great attention has been given to the nutraceuticals **glucosamine sulfate and chondroitin sulfate for the treatment of osteoarthritis**. Anti-arthritic effects in animals are now widely known. Multiple studies have been done which include symptomatic and well as objectively measured X-ray

findings, such as progression of joint space narrowing. Some degree of efficacy is probably due to these preparations but you *must* be alert to the possibility that they may not be manufactured correctly or consistently. Also, don't expect positive benefits in less than 4 to 6 weeks. Thus far, these preparations appear to be safe, but only short-term studies have been done.

HERBS TO BREATHE BETTER:

Next, let's consider some *respiratory*-related herbal issues.

~~ZZZ~~ **Zinc** preparations have been well studied and do *not* modify the duration or severity of the common cold.

~~ZZZ~~ Old fashioned, or first generation antihistamines, such as over the counter **Dimetapp, Chlortrimeton and Tavist, are effective at modifying nasal symptoms of the common cold**, whereas modern day antihistamines such as Allegra, Zyrtec and Claritin are not.

~~ZZZ~~ **Vitamin C does NOT prevent nor modify the common cold.**

~~ZZZ~~ **Echinacea** does not prevent the common cold, but it might diminish the magnitude and duration of symptoms. But don't take Echinacea for longer than 7 to 10 days, as chronic immune stimulation can lead to cancer. And I already mentioned that Echinacea interferes with the effectiveness of birth control pills.

~~ZZZ~~ There is no evidence that **gingko biloba** modifies asthma. **Magnesium** is probably not effective in treating asthma.

~~ZZZ~~ Don't take **cough drops containing menthol or peppermint**, both of which will make gastroesophageal reflux worse. GERD

is very frequently a cause of cough anyhow, and additionally taking these cough drops, will make asthma worse.

~~Do~~ Do not take **ma-huang** for asthma or anything else. It is derived from ephedra plants, and ephedrine is no longer prescribed by responsible physicians because of the much safer and more effective agents such as albuterol, terbutaline (Brethine) and salmeterol (Serevent).

Thanks again to Dr. Webb for yet another wonderful article crammed with interesting information. Are you looking forward to Part 5?

Unfortunately it will be the last in this series so be sure to watch for, "OK, then, what SHOULD I take?" --

HERB'S CURRENT RECOMMENDATIONS ON COMPLIMENTARY THERAPIES' which you can read in next month's newsletter.

DONATIONS

We appreciate all donations that come in but were especially pleased with the very generous donation for education and research sent by the **Second Wind Group**. They tell us they are a small group of about 50-60 people with various types of lung disease, but mostly COPD. This Second Wind Group is sponsored by **Memorial Hospital of South Bend, Indiana**, founded in 1993 and continuing to flourish. Thanks, folks!

And very special thanks go to **John Boynton** who again has sent in a quarterly donation.

From the mail box

End of Life Issues

Mariam Meek saves every issue of her Second Wind and shares them with the others in her complex for the elderly and even with her doctor. She admits that at first, her doctor wasn't too keen on getting her literature but now he too reads us on his computer. The residents of her complex have been discussing **end of life issues**. She writes that the words of **Dr. Petty in the January 2004** issue are the wisest that she has read. She has saved every issue of her newsletters to read again and again, but shares them with the others. Thank you for letting us know how much the article and our newsletter have helped you, Miriam!

If you missed the January issue you will find it archived on our website at www.perf2ndwind.org.

Panic Attacks

"My mother, age 59, has been diagnosed with COPD. Her pulmonary function test showed that she has very little lung capacity left. You can imagine how frightened she and the rest of the family were when we heard this. She is in a rehabilitation program and has managed to remain healthy except for the disease itself. One of the biggest problems is continuing reoccurrence of panic attacks. She has them every morning when she gets up, and some times during the day. She is on a regular regime of inhalers, breathing treatments, takes Zoloft daily, and uses Zantac when unable to get it under control. Do you know of anything that might help? She is so healthy other than this. Her quality of life would improve dramatically if she could get the attacks under control.

What a good question. We'll try to offer some general suggestions to her and to the many others who suffer from this problem. Obviously, you have first discussed this problem with the pulmonologist since only he or she is in a position to know what is really going on. Perhaps respiratory medications need to be increased or altered. Sometimes the doctor can prescribe a more effective medication at bedtime that will last all night and still be of help in the morning. It is a little-known fact that lung function has a regular variation over a 24 hour period and is consistently worse in the early morning hours. Many bronchodilators that are taken before going to bed are completely gone by the time you wake up. Newer long-acting bronchodilators may be of help because they work through the night. Serevent (salmeterol) and Spiriva (tiotropium) when taken as directed give a higher level of lung function on awakening in the morning. The combination of the two likely works even better.

The use of a rescue inhaler (a short-acting bronchodilator) on awakening might be encouraged. If there are a lot of secretions, postural drainage should be done an hour before going to bed to help remove secretions, which tend to build up at night. The staff at the rehab program should also be involved in helping. I suspect she needs more practice in proper breathing techniques, energy conservation and *pacing* herself. She can rapidly run out of oxygen if she moves too quickly, even if *she is on supplemental oxygen!*

Moving too quickly or poor breathing techniques are often the cause of panic attacks. When patients

try to overcome shortness of breath by **breathing too fast and not concentrating on breathing out twice as long as breathing in** they feel much worse.

Let's see what else we can suggest to help all those who have this problem. First, keep an **inhaler** at the bedside to use **before** getting out of bed. Then start nice, **slow**, easy, pursed lip breathing (PLB) before rolling to the side, continuing to PLB. *Slowly* push up, with one arm, to a sitting position, **exhaling with effort** through pursed lips. *Stop again* and do PLB until there is no shortness of breath. Slowly stand, being sure to exhale, or blow out, while doing so. *Again, pause and do slow*, easy PLB. Do this until there is no shortness of breath. Then walk **slowly** to the bathroom. Are you beginning to see the pattern here? Many people jump out of bed in the morning, and walk into the bathroom as fast as possible to get there before they get short of breath. Instead, they may start to panic, and maybe even lose control of their urine. *This really can be prevented with proper breathing techniques and better pacing.* Sometimes a commode can be put next to the bed temporarily until better pacing, and breathing techniques, are learned.

During the day, notice what causes panic. Let her know that she *does* have control. She *can* prevent panic if she **slows down physically, slows down breathing, breathes out 2 or 3 times longer than breathing in, and uses the rescue inhaler as prescribed by the physician.** We've exaggerated how slowly this should be done, but at first, this may be necessary. As this

pattern of slowing down and breathing properly becomes more of a habit, she probably will be able to move more quickly.

Check our Website at www.perf2ndwind.org for more on exercise, breathing techniques and pacing. Be sure to look at the old newsletters we have archived. You'll find a lot more information. Your mom is fortunate to have such a caring family! We hope these suggestions help.


Importance of Exercise

Kenneth gave us permission to write up his success story, which we will paraphrase for you. He wants you to know that YES, there is something you can do about the diagnosis of COPD! A little over a year ago he went to a VA hospital for a check up and collapsed in the waiting room. They put him on a breathing machine, which was a wake up call for him. He knew he *had* to do something. The doctor told him his condition was serious but didn't suggest anything but some inhalers. So, he started to help himself all on his own. At first, he couldn't walk more than 50 ft. **He is now up to 5 miles a day!** While walking, he does pursed lip breathing, which he learned from his niece, a nurse. He knew his weight was a factor in his breathing difficulty so, while sitting at the computer, he puts his hands behind his head and has worked up to 50 sit-ups while sitting in the chair. [We'd suggest starting with hands down, or even braced on the chair arms, or your thighs.] He also bends forward and alternates touching each elbow to his knees. Was he able

to do all of this when he first started? Of course not! He started *very* slowly. With exercise and a diet, he went from a 45 inch waist down to a 31 inch waist, and has regained 10% of his breathing ability! The VA was so impressed by his improvement that he was asked how he did it. They didn't believe it was possible and are planning to monitor this closely for the next few years. With the idea of encouraging similar programs in other COPD patients, we hope! Kenneth tells us that he now feels better than he has in the past 10 years. He is 68, doesn't wheeze anymore, and can do anything he wants to do without fear of running out of air. He hopes his words help all of *you* out there reading this. He knows how you feel because he has been there.

What impresses us so much is not just the improvement, but that he did this all on his own without any help. That is what makes this such an inspiring story. Kenneth, we salute you!

NEW SEARCH TOOL on PERF Website

Do you try to find articles on something specific but don't know where to start? Go to <http://www.perf2ndwind.org> and look at the very bottom of the page. Type in the name of what you want to look up, e.g. oximeters. Click the SEARCH button and it will list all the references we have. Want more information? Click the radio button for "WWW" and Google will search for anything else available on the Web. Try it the next time you are on line. It is really neat! 



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DROWNING IN SALT (Part III)

Dear Friends:

The first two installments of this series of newsletters have dealt with the importance of salt in health and disease, and how salt has been critical in the preservation of food plus allowing man to travel across continents and seas (see April and May issues of "Second Wind").

Salt is almost ubiquitous in our diet. Sodium is the key part of salt that we must control. Baking soda is sodium bicarbonate and bottled drinks such as Perrier, which contains sodium sulphate, has a lot of sodium that must be considered. The component of salt known as "sodium" is critically important to the maintenance of health and the prevention and management of disease.

Don't trust nutritionists or dietitians to advise you about salt. Surprisingly, many know very little about it. Also don't trust a low salt diet given in a hospital. It can be extremely salty because of lack of information on the part of the nutritionist and all the way down to the preparation staff.

Normal salt requirements are somewhere between above 500 mg and 1000 mg per day. The Western diet commonly contains 5-6 grams of salt, which is quite excessive for normal needs. The Japanese consume 10 grams of salt daily. There are 10 grams of salt in a large dill pickle! Sauerkraut is loaded with grams of sodium. Most soups have at least a gram of sodium. All prepared foods have salt, such as lunchmeats, condiments, i.e., mustard, ketchup, mayonnaise. Even bread, cereals, and milk contain significant sodium. Ham, beans and most cheeses are loaded with sodium. Doritos, Fritos, potato chips, salted nuts, etc. are other places where salt is highly unnecessary. Even baby food contains salt. This is because mothers taste the food and feel that it is bland without salt. More on salt in the final installment.

I'll be in touch next month.

Your friend,

A handwritten signature in black ink, appearing to read "Tom Petty".

Thomas L. Petty, M.D.
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