



Second Wind

NEWSLETTER

May 2006

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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KEY WORDS: Rubye Richey, Beta Blockers, Home Oxygen Patient Protection Act" (H.R. 5513, Front Line Advice, Emphysema/COPD Jr., Essentials of Pulmonary Rehabilitation, Benefits of Pulmonary Rehabilitation, Breathing techniques, Sodium free pickles, Letter fro Tom



Exercise is important but socializing and the friendships made here are also very important.

Did you notice that there is a new name listed in our PERF Board of Directors? We would like to

officially welcome **Rubye Richey** and tell you a little about her. Rubye fills a role in PERF that has been empty much too long, that of a patient advisor. While PERF is very patient oriented we want to make sure that we always have the patient's viewpoint in mind. Rubye will help us do that. Rubye graduated from Mary Burns' pulmonary rehab program about 15 years ago. She made fantastic improvements during rehab and hasn't slowed down since. She is an ardent supporter of rehab and the value of exercise! She remains on the

Patient Board of the PEP Pioneers at Little Company of Mary Hospital, helps with PERF mailings and has attended several PERF Board meetings over the years.

You may have seen our dear Rubye in one the slides that Mary uses to illustrate talks she has given around the world. The picture above shows Rubye with classmate Carol Hoshiko exercising at the highly successful program for COPD patients run by Tom Storer, PhD at El Camino College. We all welcome our friend, Rubye Richey, to the PERF Board of Directors!



BETA BLOCKERS

In addition to the emails that come into the PERF office asking for advice and information there are handwritten letters and occasional telephone calls. What is printed in the newsletter is a composite of our answers to the most common problems we have heard in the past few months. Every response, whether published or not, is edited for accuracy and appropriateness by our medical team. We always try to caution you, answers can only be *very* general. Only your physician has access to all of your records and has also done the thorough physical examination needed to truly evaluate and advise you about the complex problems you often present us with.

There are exceptions to everything, however. This month we are focusing

on only one patient and his trials and tribulations. We are writing this article, and releasing some of his medical information, *at his specific request*. He has a mission! He doesn't want anyone else to suffer as he did. He is sure, as are we, that he is not the only one who has had a similar unfortunate experience. Hugh is committed to warning all pulmonary patients, and all of their healthcare team, to be aware this very serious, preventable problem.

Hugh first contacted us by phone. He came across as being intelligent, well educated, knowledgeable about his disease and factual in his presentation of his problem. In fact, he was remarkably calm as he presented his case history as carefully as a physician making Rounds with interns.

Until about late June of last year, he had no problems. He was extremely active riding his mountain bike about 5 miles, 6 days a week, up and down hills with only normal shortness of breath. He had seen his family practice physician in June and had medication prescribed which lowered his pulse from 96 to 69. In the weeks that followed he started noticing shortness of breath. By September he was suffering from extreme shortness of breath with exercise and returned to his family practice physician.

Hugh outlined all the steps taken to diagnose his problem and they were impressive.

- 9-2-05 a CT scan showing diffuse emphysema
- 9-5-05 a pulmonary function test (PFT) showing an FEV₁ (forced expiratory volume of air in one second) 30% of predicted. His FVC (forced vital capacity of the lung) was only 52% of predicted. It felt to Hugh as if he had lost 50% of his breathing capacity in the last 90 days.

His family practice physician, and the pulmonologist now also seeing him, attributed this to 50 years of smoking 2 packs a day. Hugh agreed this was a reasonable assumption but couldn't understand why he had such a rapid decline in pulmonary function. Nevertheless, he quit smoking yet continued to feel worse.

- 11/18/05 a treadmill test was halted when he had a panic attack.
- 11-30-05 an angiogram, showed that he had "the heart of a 35 year old and no blockages." His problem was not cardiac in origin, according to the cardiologist to whom he had been referred.

Hugh started a pulmonary rehabilitation program, which helped by giving him lots of tips in managing his increasing inability to handle activities of daily living, BUT his

exercise capacity continued to decline, rather than improving with rehab. Taking a shower caused him to break into a sweat and required 10 minutes in bed on oxygen to recuperate. Though he was on oxygen with exercise, he was still desaturating, with marked shortness of breath, biking only 15 minutes with 2 rest stops. This was a man who had been riding mountain bikes 1-½ hours without stopping 3 months earlier. Nothing he tried, none of the medications and inhalers he was prescribed, were helping. His pulmonologist told him there was nothing else she could do. Hugh was understandably depressed.

Hugh called the PERF office over the New Year's holiday to see if he could arrange an appointment with Dr. Petty, or get a recommendation for where he might get lung surgery. He felt he had exhausted all other options and was desperate. He said he kept insisting to his physicians that something other than smoking or the normal course of COPD must have been causing his problem. A 50% decline in lung function in such a short time did not sound logical to him.

Here was a man who had the best of care including referrals to a cardiologist, a pulmonologist, extensive testing (which ruled out cancer of the lung among other things), and finally, referral to a

pulmonary rehabilitation program. His list of pulmonary medications was all that could be expected. He doggedly continued to try to exercise, which became more difficult all the time. His care seemed excellent yet his history was far from typical. There certainly was nothing that could be done over the phone except to suggest a consult with another pulmonologist.

Dr. Petty couldn't see him as a private patient but strongly agreed that Hugh should see one of the fine pulmonologists in this area. Since Hugh was local we were able to highly recommend someone known as an excellent diagnostician. This physician was affiliated with Cedars-Sinai Medical Center so he could also evaluate Hugh as a candidate for surgery if that became his only other option.

Hugh called back a few weeks later. Before seeing the new pulmonologist he had another pulmonary function test. The bad news was that it showed his FEV₁ was now down to 28% of predicted. The good news was less than five minutes into his appointment the new pulmonologist had discovered his problem! Hugh's difficulties, unknown to him, had started back in June when he had been placed on a cardiac medication called Nadolol to lower his pulse rate. Nadolol is a beta blocker. Beta blockers are usually contra-indicated in pulmonary

patients since they can often (though *not* always) cause bronchoconstriction, or spasm of the airways resulting in shortness of breath! In spite of the best of care, Hugh had fallen through *all* the cracks. His primary physician, the pharmacist filling the prescription, the cardiologist, his *pulmonologist*, the pulmonary rehab team and even the pharmacist working the rehab team had *all* missed the significance of his shortness of breath and bronchospasm after being put on the Nadolol.

So what happened to Hugh? He stopped taking the Nadolol immediately. By April his FEV₁ was up to 45% of predicted. His FVC was back to a more normal 82%. His peak flow went from a daily average low of 150 to a 320 to 460. He is again riding his mountain bike 1 ½ hours six days a week, using oxygen only on the last uphill leg. Oh, yes, and he can take showers again without any problem! In June he is going on a 3-week tour of Scotland and England. He feels great! His advice to all of you?

No matter how excellent your medical care seems to be, you must take some responsibility for your own well being!

Read all those inserts you get with your prescriptions!

If you ever get one that says it is a beta blocker, or contraindicated for those with emphysema or COPD, don't take it without first discussing this very thoroughly with your physician! We might add that this applies even to medications like beta blocker eye drops, which have gotten more than one of our patients into the type of problem that Hugh experienced.

However, each of you is unique and different. Not everyone reacts as negatively as Hugh did. It may be that in your case a trial with a beta blocker may be indicated because of a cardiac problem. But it is very important to be aware of the possibility of developing the symptoms of shortness of breath and notifying your physician about this common side effect immediately.

Dr. Casaburi, in reviewing this newsletter, wanted to chime in with a little more information. Some beta-blockers are "cardioselective": they tend to influence the heart but not the lungs. These cardioselective drugs have been shown to be relatively safe in patients with lung disease. Unfortunately, Nadolol is *not* cardioselective and seems to be a poor choice for a patient with COPD.

Hugh suffered, and survived a terrible 6 months. We know all of you appreciate his wiliness to share this experience with you. If he can spare

even one of you from going through a similar experience he feels his mission is accomplished. Thanks, Hugh for allowing us to tell your story!



Many thanks to all who so generously remember PERF

We would like to thank Bill and Virginia Ellis for their donation to PERF and their very nice note.

John & Mildred Boynton made another donation for Chair while Kevin and Judy Hettich wrote several nice letters and made two donations to the Chair in honor of Mary Burns. (Two! Thanks so much...to the two of you! MB)

Memorial donations were made by Jim Wood in memory of Carlin Wood, by Jean and Al Hughes in memory of Edward Gorman, by Jackie and Ken Rubinwitch in memory of James Hickey, and by the PEP Pioneers in memory of Mervin Sebring, Mark Bixler. Betty Netherton, Janey Vickrey, Dawn Dieterle, Joyce Lonergan, Vy Young, Dan Yamada and Jack Moceri. Memorial donations were also made by Nancy Krawczeski (Mayfield Elementary Sunshine Club) for Nancy McGrath and by Barbara & Harold Borak for Mary Ann Mennenga.

Donations were also made by the Bush Family, Mirna & Curtis Stanley and Sheri & Kevin Fenenbock, Inge &

Gerald Plier, Rob & Dianne Wilson, Victor & Marjorie Dugger, Mr. & Mrs. M. Ehrlich, Mr. & Mrs. Thomas Getzfrid, Mr. & Mrs. Thomas Johnson, Mr. & Mrs. J. Weldon, Robert & Joan Uzes and Bruce & Karen Beckley in memory of Katie Beckley. Mary Burns made a memorial donation for Sal Rossito.



Bill Probsfield, the grateful recipient of a double lung transplant, sent us this bumper sticker he supports: "*Don't send your organs to Heaven when Heaven knows they are needed here!*". We're with you, Bill!



Very important news!

Rep. Joe Schwarz (R-MI), a physician, has introduced a bill to reverse the oxygen provisions of the, Deficit Reduction Act #S1932. This new bill is called the "Home Oxygen Patient Protection Act" (H.R. 5513)

As you may know, last minute language was inserted into the Deficit Reduction Act of 2005 (DRA) mandating that Medicare beneficiaries assume ownership of their oxygen equipment after 36 months. This countdown went into effect January 1 of this year, 2006. There have been many serious concerns about the financial and safety implications for vulnerable oxygen users as well as about the many ambiguities of this bill. Advocacy groups and other stakeholders visited Capitol Hill

numerous times following the passage of the DRA. Many emails and letters were sent in efforts to inform the legislators, and their legislative staffs, about this oxygen provision and the many ways it might negatively impact their constituents on oxygen.

On May 25, Congressman and medical doctor Joe Schwarz (R-MI) introduced the **Home Oxygen Patient Protection Act**, or **H.R. 5513**. Co-sponsors include Rep. Tom Price (R-GA), also a physician, Rep. Ralph Regula (R-OH), Rep. Patrick Tiberi (R-OH), Rep. David Hobson (R-OH), and Rep. Tim Ryan (D-OH).

The bill amends part B of title XVIII of the Social Security Act to *restore* the Medicare treatment of ownership of oxygen equipment to that which was in effect *before* enactment of the Deficit Reduction Act of 2005.

We hope all homecare providers, patients, and their families as well as their medical teams will support Congressman Joe Schwarz. We urge you to email him and other Members of Congress, especially your state representatives, to cosponsor and pass this extremely important bill, HR.5513!

Send your emails in today!



Do you have a copy of this book?

We highly recommend it! To order go to www2.xlibris.com/bookstore

Frontline Advice for COPD Patients



A Book by James T. Good Jr., & Thomas L. Petty

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Have you seen **EMPHYSEMA/COPD: The JOURNAL OF PATIENT CENTERED CARE?**

Volume II, Number 3-4 Summer/Fall 2005 issue reprints the PERF booklet *Essentials of Pulmonary Rehabilitation. A Do It Yourself*

Guide to Enjoying Life with Chronic Lung Disease written by Dr. Tom Petty, Dr. Brian Tiep and Mary Burns. For more information about ordering this excellent bi-annual Journal telephone (321) 751-0340.



Benefits of Pulmonary Rehab

It has been years since we heard from **Carolyn Dearen** who made Mary's day by calling lately to say hello. She reminded Mary of how sick and physically limited she had been when she started rehab, and how much she had improved during the 6-week program. With justified pride, Carolyn said she had never forgotten the lessons of rehab. She is very faithful about daily exercise.

Currently she is swimming 40-minute daily laps and walking in an indoor lap area since she lives in hot Sun City, AZ. Carolyn reports she rarely has an exacerbation (infection) except after a long plane flight. She generously attributes maintaining her health and exercise regime to what she learned in pulmonary rehab. How long ago was that? *Twenty-two years ago!* Who says improvements made in pulmonary rehab don't last? Not Carolyn!



Carolyn's testimony about the value of exercise and rehab is a personal confirmation of research presented at the recent **CSPR (California Society of Pulmonary Rehabilitation) and ATS (American Thoracic Society) annual meetings** in held in San

Diego this May. We will have lots and lots of new information for you in the next Second Wind but briefly, a minimum of thirty minutes of daily exercise such as walking is one of the best things you can do to promote a better life and a longer one.

Pulmonary rehabilitation is what is recommended as the best way to gradually accomplish this increase in exercise tolerance and also to decrease depression and acute exacerbations.

Breathing techniques learned in rehab make exercising easier. Pursed lip breathing combined with slow respirations, and breathing out longer than breathing in are what you should aim for. By slow we mean *under* 16 breaths a minute. **Research shows that even 20 breaths a minute can cause a marked increase in air trapping, which causes increased shortness of breath and feelings of suffocation.** We now have proof for what we have been telling you in rehab for many years. This is one time when you can't trust your instincts. When you feel the most short of breath may be the time you need to stop, and do your best to *slow* your respiratory rate! We'll give you more details on this and other important issues in the next Second Wind.



This is the pickle recipe by Louise Nett that got Dr. Tom Petty in a

pickle..... which you can read all about in his letter on the next page.

Sodium Free Pickles

Soak pickles in cold water for an hour.

Put pickles in clean quart jars (sliced or whole small ones).

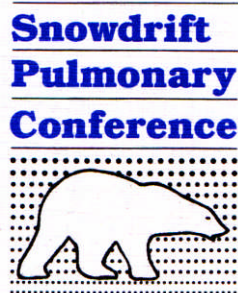
Heat 1-cup water and 1-cup vinegar in micro wave till hot.

Add spices.....dill, cumin, bay leaf, Italian mixed spices, whole cloves, garlic, onions etc (plus sugar or Splenda if you like them sweet).

Pour over pickles.....they will be ready to eat tomorrow.

As most of you know, Dr. Petty has had many very serious health problems the past few years. We get many concerned questions about how he is doing along with requests to let him know that people are thinking of him and praying for him. When we delivered that message he asked that we publish the following reply.

“I am moved to know that people care and pray for me. This keeps me going. Give them this message of love.” **Tom Petty**



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Second Wind
Lomita, California

Dear Friends,

Don't Get Yourself in a Pickle!

Historically, getting in a pickle meant a predicament. It derives from the Dutch, "in de piklel zetten," which literally means sitting in the pickle brine, full of salt and irritation.

I have commented before about the high content of salt in canned pickles, up to three grams (3000 mg) in a medium sized dill! This would put any person with heart disease in more edema, i.e., a predicament (pickle).

My associate, Louise Nett, has a recipe for sour pickles that accompanies this issue of *Second Wind*. They are great and add zest to a sandwich or salad. I started to get hooked on them, for their flavor, and without salt! Amongst other medications that keep me going, I have to take Coumadin to reduce my clotting mechanisms. Coumadin is commonly known as a "blood thinner." The activity of Coumadin is frequently monitored by measuring the INR, which is known as the international neutralization rate (of a clotting process).

Shortly after appreciating Louise's salt free pickles, I found out that my INR was way down, meaning that the Coumadin was not controlling the clotting process. The answer had to be the vitamin K in pickles. Vitamin K counteracts the effects of Coumadin on some clotting factors, and thus mitigates the tendency to form clots in the legs, lung, heart and brain. Maintaining a therapeutic range INR is extremely important for persons requiring this drug.

The main sources of vitamin K in the diet are green leafy vegetables, broccoli, and Brussels sprouts. Also vitamin K is in Centrum and other multivitamin preparations. There is no mention of vitamin K in pickles, in any dietary manual that I could find, but now that I control my pickle consumption, my INR is easy to maintain again.

I thought these facts would keep some of our readers from "getting in a pickle!"

I'll be in touch next issue.

Your friend,

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

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