



Second Wind

NEWSLETTER

OCTOBER-NOVEMBER 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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PERF, Alvin Grancell-Mary Burns Chair of Rehabilitative Sciences, Dr. Casaburi, Dr. Petty, Advice on flu, Tameflu, Mark Junge, Tranquillizers, Advair recall, World COPD Day

The PERF Board members are all volunteers and busy ones at that.

October 2nd was a **COPD/Alpha-1 Education Day**, which they have been helping with for months. You saw the proposed schedule in our last newsletter. Its successful dawn-to-dusk completion came after 4 talks by Dr. Casaburi, 2 by Dr. Tiep and a short one each by Jim Barnett and Mary Burns. Rich and Mary (with the assistance of Brian Tiep) acted as moderators and timekeepers in the separate tracks for patients and health care professionals. Mary had hoped to take notes but was too busy with keeping time and other duties in the professional track she was monitoring for any meaningful notes on the 10 different lectures that were presented. That's right, ten! It was a busy day crammed with information from doctors volunteering their time and expertise. There were about 140 in the audience and there could easily have been 100 more, according to disappointed absentees. Well, the important thing was the enthusiastic response of all who were present. It helped make the day worthwhile for those of us there from dawn to dusk. Mary Burns gave a short explanation of the nuts and bolts of PERF, which we will repeat here.

“The Pulmonary Education & Research Foundation, PERF, was conceived, and largely financed, by Alvin Grancell. Alvin is the widower of one of my very special patients, Mary Grancell. He originally wanted a foundation focused narrowly on pulmonary rehabilitation programs. That scope widened very quickly. PERF is now associated with many national organizations as well as local ones such as CSPR, the California Society of Pulmonary Rehabilitation. We support all aspects of pulmonary

rehabilitation. Our newsletter, *The Second Wind*, is read around the world. Our website is geared toward both patient and professional and updated weekly by our Webmaster, Dr. Janos Porszasz, a pulmonary scientist.

Very early in the game the PERF Board recognized that it was necessary to support research that contributed to the scientific basis for pulmonary rehabilitation. Specifically, *clinical* research; the type of research needed to improve and lengthen the lives of those with pulmonary disease *in the short run*. Many of you in the Southern California area in particular have benefited from this research that is just beginning to impact other parts of the country and world.

How many of you do pursed lip breathing? Do you know that an investigation of PLB was the first study funded by PERF way back around 1985? As most of you know, we showed that done correctly it can raise the oxygen level of the blood, while done incorrectly it lowers it. Some parts of the world still don't understand that. Back in 1989 we also had a small but important study showing that PLB helps those with restrictive disease. No one thought this was possible until one of my patients noticed this when practicing breathing techniques with one of the first oximeters in Southern California; donated to the rehab program by Alvin Grancell. We listen to patients and learn a lot from you!

Do the benefits of high intensity exercise sound familiar to you? It doesn't to many pulmonary patients in the world. How about the benefits of lightweight portable oxygen and oxygen with exercise? Do you know that about 80% of folks on portable oxygen in the United States have E-cylinders? How about the benefits of oxygen on improving exercise in patients whose oxygen levels don't now qualify them for oxygen? Seed money from our small foundation has helped these studies.

While all patients with pulmonary disease have benefited from our work, those of you so close to us in Southern California have probably benefited the most. You have volunteered for our studies, and learned. Your patient groups have socialized with each other at Rallies and events like this, and learned. Quarterly and annual meetings involving PERF Board members have kept local rehab staffs on the front line of learning and utilizing new concepts long before they get published.

In order to insure a mission that would continue to grow and help pulmonary patients for many years to come, Alvin pledged his entire estate to fund the **Alvin Grancell-Mary Burns Chair of Rehabilitative Sciences**. *This is the world's first endowed chair supporting a pulmonary rehabilitation scientist*. What is a University Chair? It is created by a fund set aside for a specific purpose, in this case, pulmonary rehab. The *interest* from that fund is used to support a scientist *in perpetuity* since the body of the fund is never touched. About two million dollars is now about the minimum bequest required to accomplish this.

Two years ago, the Chair was established in the Los Angeles Biomedical Research Institute at the Harbor-UCLA Medical Center with the pledge of future adequate funding. Dr. Richard Casaburi was the first designated holder of the Chair.

Rather than doing this posthumously, as is usually the case, Alvin has magnanimously provided enough funding so that this dream could be achieved during his lifetime.

On January 1 of 2005 Dr. Casaburi will resign as chief of pulmonary services at Harbor-UCLA and formally occupy the Alvin Grancell-Mary Burns Chair of Rehabilitative Sciences, the first Chair in the world devoted to pulmonary rehabilitation. This is a momentous occasion for all of us.

PERF is also blessed with a dedicated, savvy Board. We have made major accomplishments with small amounts of money, some of it donated by you. The Chair is established, but our goals remain ambitious as the needs of pulmonary patients around the world grow. When Rich Casaburi, or Tom Petty, make an annual appeal for funds next month, remember our history of accomplishment. Donate if you can, and send us your best wishes if you can't. Those good wishes also mean a lot, and inspire us to continue with our mission of helping those with pulmonary disease. Thanks to all of you."

PERF Fundraiser

The next day was equally important, but much more relaxed. The Board, and about 48 other guests, attended "an elegant afternoon of music" at the PERF fundraiser held in the West Covina home of Barbara and Harry Borak. Did you know that Dr. Brian Tiep IS a gifted musician able to play the violin, mandolin and almost any other stringed instrument with equal skill? Brian, his daughter Rebeca on the violin, and Gary Ibarra on the classical guitar, played together while 11-year-old Adam Alvarado, a future physician, played some elegant classical music on the piano. Brian and Rebeca later roamed the group, informally playing any requests. Their repertoire seemed unlimited! It reminded a few of us of all the times they had entertained us at past Rallies and CSPR meetings. Such multitalented people never cease to amaze those of us that aren't.

Dr Petty wasn't able to join us at these functions but he is amazingly busy as he continues to improve after his 4th heart surgery. He is editing a new book on "**Pulmonary Disorders of the Elderly (Diagnosis, Prevention and Treatment)**" which will be shown at the American College of Chest Physicians (ACCP) in Seattle this month.

AARC, The American Association of Respiratory Care, has been getting a lot of questions and asked if Dr. Petty could help them out. He replied, with typical enthusiasm, that he loves doing this kind of thing! The debut of "**Ask Dr. Tom**" will coincide with the celebration of **Respiratory Care Week, beginning Oct. 25**. In the online column, he will be available to answer your questions about lung disease and care located at:

http://www.aarc.org/headlines/lung_health_day_04/dr_tom.asp

Advice on Flu

We got in ahead of the crowd and asked Dr. Petty for his advice for those of you who were not able to get that all-important flu shot as yet. We got additional information from the official CDC government website.

Symptoms of flu include:

- fever (usually high),
- headache,
- extreme tiredness,
- dry cough,

- sore throat,
- runny or stuffy nose, and
- muscle aches.



- Gastro-intestinal symptoms, such as nausea, vomiting, and diarrhea, are much more common among children than adults.

How Flu Spreads

The main way that flu is spread is from person to person through coughs and sneezes and respiratory droplets. Occasionally a person may become infected by touching something with a virus on it, and then touching their mouth or nose. Avoid unnecessary contact with children! The little darlings are not too good about hand washing which leads us to one of the most important things you need to do also; don't forget to **WASH YOUR HANDS!**

The incubation period for influenza is 1–4 days, with an average of 2 days. Adults may be able to infect others beginning 1 day **before** getting symptoms and up to 7 days **after** getting sick. **That means that you can give someone the flu before you know you're sick as well as while you are sick.** Children can be infectious for 10 days

Good Health Habits to Prevent the Flu

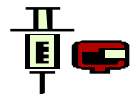
- **Avoid close contact with people who are sick.** When you are sick, keep your distance from others to protect them from getting sick too.
- **Stay home when you are sick.** If possible, stay home from work, school, and *errands* when you are sick. You will help prevent others from catching your illness.
- **Cover your mouth and nose.** Cover your mouth and nose with a tissue when coughing or sneezing. It may prevent those around you from getting sick.
- **Clean your hands.** Washing your hands often, or using alcohol-based hand rubs, will help protect you from germs. Sometimes flu can be spread when a person touches droplets, nose drainage or saliva from an infected person, or a soiled object, and then touches one's own (or someone else's) nose or mouth before washing hands.
- **Avoid touching your eyes, nose or mouth.**

Complications

Influenza illness typically resolves after a limited number of days for the majority of persons, although cough and malaise can persist for more than 2 weeks. Some of the complications caused by flu include a secondary bacterial pneumonia or primary influenza viral pneumonia, or a co-infection with other viral or bacterial pathogens. Also possible are dehydration, and worsening of chronic medical conditions, such as congestive heart failure, COPD, asthma, or diabetes. Children may get sinus problems and ear infections.

We hope, and assume, that you have had your "pneumonia shot" which offers protection against the most serious bacterial pneumonias!

If you haven't yet gotten your flu vaccine make sure you are on your doctor's top priority list so that you can be called should your physician get in more vaccine. If you don't call, the office personnel may think you got your vaccine down at the local grocery store or rehab program.



We are already being bombarded by health food store recommendations to take mega doses of Vitamin E or other health supplements. That can be expensive with no research demonstrating any benefits. Do continue to take your multi vitamin every day.

FluMist

You may also have heard of the nose spray vaccine. Sounds like a great idea, doesn't it? Unfortunately, is not appropriate for most of our readers. FluMist, the nasal spray influenza vaccine that contains the weakened live virus, should be used only for *healthy* children and adults between 5 and 49 years of age. It is recommended for those around high-risk individuals. The nasal spray vaccine can cause you to develop symptoms similar to a cold, but it does *not* cause the flu. If you become infected with the flu despite having been immunized with the nasal spray vaccine, symptoms will usually be mild, and you will have a decreased risk for developing flu **complications**.

People who are at risk for severe complications from the flu should **not** receive the nasal spray vaccine. This high risk group includes:

- Children younger than 5 and adults older than 50.
- Pregnant women.
- People of any age with certain medical conditions, such as chronic heart or **lung disorders**, diabetes and other metabolic diseases, kidney problems, or blood conditions.
- People who have an **impaired immune system** or who are receiving medications that affect immunity, as well as their close contacts, such as caregivers or family members.
- Anyone younger than age 20 who is on long-term aspirin therapy because of their increased risk for developing **Reye's Syndrome**.
- Anyone who is allergic to eggs or any component of the vaccine.
- People with a history of **Guillain-Barré syndrome (GBS)**.
- Anyone who has a high fever. The vaccine can still be given if an otherwise healthy person has a minor illness, such as a cold.³

Relenza

Additional words of wisdom from Dr. Tom are to warn you that **Relenza (zanamivir) is not popular as an inhaled antiviral agent because it can cause significant bronchospasm**. Who needs more of that!

Tamiflu

The best antiviral at this time is Tamiflu, or oseltamivir. A 75 mg dose is taken once a day for prophylaxis (prevention), and twice a day to abort an attack if you have been exposed, or think you are coming down with the flu. It is a neuraminidase inhibitor, i.e., it stops one mechanism of viral replication. It works on all A and B strains. It is very effective with few side effects and essentially no drug interactions. That's what we all like. *But*, it is expensive, which we don't like. The prices probably vary a lot according to the pharmacy you use but can be as much as \$6.00 per pill. *But*, dear friends, consider the costs of the possible alternatives. It is better than risking influenza, which is lethal to older people with chronic illnesses and to the very young. Dr. Petty says it is worth it to him. He intends to take **Tamiflu** this year during attendance at the ACCP in Seattle, mid October. Of course, he'll take it sooner if he thinks he is coming down with the flu with the symptoms of **cough, fever and severe muscle aching**. Diarrhea alone, wrongly called the "stomach flu", has nothing to

do with the influenza viruses. Neither does the sneezing and runny nose of a common cold. These symptoms are very annoying, but will NOT be helped by these antivirals.

Amantadine (symmetrel) and Ramitidine

Getting back to antivirals, you should know that there are some that are much cheaper than Tamiflu. They are Amantadine (symmetrel) and Ramitidine. Both work on all A strains, but *not* on B. The good news is that the B strains almost never cause epidemics. The not-so-good news is that these drugs can cause Central Nervous System (CNS) side effects such as insomnia, anxiety, etc. They are not *too* bad, compared to the real flu, and the symptoms are reversible.

So there you have the latest information. You may want to take one of these antivirals if you are exposed to large crowds, such as those Dr. Petty expects in Washington. ***You definitely should take antivirals the very first day you come down with symptoms of fever, cough and severe muscle aches, or the second day at the latest, to get the full benefits. Good luck and Gesundheit!***

PERF Sends Many thanks to Bill and Kathleen Beckley who donated to Tom Petty's Independence Day Fund, John Boynton who made another quarterly donation, Mickey Heumann, and Inogen, Inc developers of the new oxygen concentrator soon to be allowed on airplanes and Kevin & Judy Hettich. We also thank Dr. & Mrs. Elton Chatfield who joined many others, including the Board, in donating to PERF at a musical event held by Barbara Borak in her home in West Covina, CA.

Jackie Rubinwitch, Ann Wentink and Mary Burns made a donation in memory of their very dear friend and classmate from Hartford Hospital, Genny Smolenski Schaniel. Jeanne Rife made a donation for Iva Lee Douglas. The PERF Board of Directors individually made donations in memory of the mother of Jim Barnett, a fellow member of the Board. Lawrence & Therese Amidei, John & Myrna Powrozek, Bernadette & William Dalenberg, Dorothy Fisher and Constance Lucchese all made donations in memory of Louis Lucchese. Constance Lucchese also made a donation in memory of Camille Kryzwar.

Special greetings to Bill Gibson and Marie Cooper.

Do you remember Mark Junge? Mark is the 61 year old man on oxygen 24/7 who decided to bike across the States to show it could be done. Well, he showed us! Mark had a well deserved victory celebration in Times Square, NYC at the successful completion of his historic trek. The achievements of people like this are beyond words and beyond awesome. Mark, we salute you!

We Get Mail on Tranquilizers

We often get questions about tranquilizers so we thought this letter would be well worth sharing, especially with the upcoming stressful holidays.

Sherry writes, "Should COPD patients use Xanax? There seems to be a disagreement in our support group. There seems to be a disagreement among our doctors too. Many of us are



using Xanax now and have been helped a lot by it. Others say it can be dangerous. The research I've been able to find seems confusing at best. Please help."

The staffs of pulmonary rehab programs often comment on how rehab improves a patient's sense of well being and eliminates panic. We speculate that breathing retraining, learning to pace, and markedly increased exercise tolerance are largely responsible for this marked change. Going along with this is a decreased request for tranquilizers.

We asked Dr. Tiep what his advice would be. He responded, "Xanax is a tranquilizer like valium. As such it can be a respiratory depressant. Dr. Richard Light and others studied it for reducing dyspnea in highly dyspneic patients. The results were disappointing - MS [morphine sulfate] is much better. My greatest concern is when patients take it at night and run the risk of respiratory depression. Also, it is very hard to get patients off because of its addicting potential. Originally marketed as being non-addicting, one study showed that patients became addicted in 3.5 days compared to 6 days for valium. The COPD guidelines on Hypnotics and COPD state, "Hypnotics, particularly benzodiazepines, should be avoided, if possible, because of a potential deleterious effect on ventilation, although there is evidence that some hypnotics, such as zolpidem, can be used in less severe COPD without significant adverse effects on gas exchange." Thanks, Dr. Tiep.

Does this mean no one with COPD should ever take tranquilizers? Of course, not! Let you doctor know if you are suffering from anxiety! Your physician has the whole picture of your medical and family history. That is who should decide if you would benefit from short-term assistance. (And don't forget to ask about a pulmonary rehab program!)

Oximeters have been the subject of other mail. Jim Frejlach says he got a Nonin at Turner Medical for a total \$287.00 without a case. Med-electronics says that their Nonin is \$277.00 and you can call them toll free at 1-888-321-1300 for more information. Of course, there is always their website at www.med-electronics.com. They say they have another brand of oximeter for only \$199.00 but we haven't had time to research it. Our apologies also to 2 other letter writers providing information on these oximeters that we are unable to locate. Who worries about witches while suffering from curse of the 21st Century, computer glitches!



IMPORTANT ANNOUNCEMENT

You probably already have this information but it is worth repeating. Please be advised that due to an isolated manufacturing issue, **GlaxoSmithKline (GSK) has recalled a small number of Advair 'Diskus' 100/50 mcg lots**. Patients should *not* discontinue use of Advair, but should check the lot number and get replacements of any products in these particular lots. Lot numbers can be found printed on the label in the center of the "Diskus", on the foil over wrap, and on the box. If patients have any difficulty reading the lot number, they should check with their pharmacist. The following 25 lots of product are potentially affected:

4ZP2067

4ZP2104

4ZP2201, 4ZP2216, 4ZP2217, 4ZP2229

4ZP2377

4ZP2474, 4ZP2475

4ZP2619
4ZP2759
4ZP2807 ,
4ZP2913, 4ZP2901
4ZP3041, 4ZP3042
4ZP3139
4ZP3244, 4ZP3272
4ZP3373
4ZP3444
4ZP3504, 4ZP3550
4ZP3631, 4ZP3659.

Patients who identify that their inhaler is from any of these lots should return it to their pharmacists, and they will be issued a replacement, free of charge. If you require additional information, you can call the **GSK customer response center at 1-888-825-5249, Monday-Friday, 8am-8pm Eastern Time.**

World COPD Day is November 17th.

See if you can find at least one person to educate about this 4th largest cause of death in the world. I'll bet it won't be hard!

Did you know (according to the Berkeley Wellness letter of October 2004) that 75 % of the sodium Americans eat comes from processed and fast foods, not from their salt shakers? 1 tsp. of soy sauce has 1030 mg. of sodium. And did you know that chopsticks are said to be the simplest, most popular hand tool ever invented and that 1.5 billion people use chopsticks daily? Mary will give you her opinion on chopsticks in the next newsletter when she returns from her trip to Japan and China. She has been honored by another invitation to talk to pulmonary patients and health care personnel in Japan. She wanted to send special thanks to Bill Wright and Vlady Rozenbaum for the digital pictures they contributed to help update those she lost when her hard drive crashed. She'll be using some of them during her talks in Japan. Our Japanese friends are eager to learn more, and interact more, with the patient support groups in the United States? They've suggested setting up a meeting someplace between the two countries like Hawaii. Would any of you be interested? Jim Barnett is already talking about organizing another cruise so that his group could participate so the excitement is building. We'll keep you posted and let us know if you are interested in a parley under the palms.

Since Mary won't be back until the middle of November **there will be no additional November newsletter.** Watch the mail early December for your next Second Wind. Until then, stay well! ♥♥♥

Happy Halloween



Happy Turkey Day!

**Snowdrift
Pulmonary
Conference**



**The Snowdrift
Pulmonary
Conference**

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October 2004

Dear Friends:

WHY DO YOU NEED A MAP?

We are all preoccupied by finding our way through a morass of highways, cities and neighborhoods. We can't go anywhere without a map. Our cars even have a "location finder." These are based upon the global position system (GPS), which uses satellite technology to tell us exactly where we are within a matter of a few feet. If we wonder off the pathway to our destination, it tells the correct course.

I marvel over how the Vikings were able to explore North America and, perhaps, other parts of the Western Hemisphere without any map. Their only navigation system was celestial but it was remarkably accurate. When Christopher Columbus embarked for Asia, he didn't know he was going to run into America and the Caribbean Islands. How did he find his way back home without a map? Again, stars and the moon, as well as constellation of planets, provided the guidance for his longitude and latitude.

It takes an immense amount of mathematical, astronomical, and computer technology to circumnavigate the earth in a satellite, reach the moon or the planets. These astronomical adventures are well planned based upon emerging technology.

All knowledge begins with observations. Finding one's way in life without a map may actually have some advantages. By exploring life without a map, it is possible to find things beyond one's greatest imagination! Such was the case of Columbus.

As we continue to explore ourselves and life's adventures, we may not need a map.

I'll be in touch next month.

Your friend,

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