Second Wind
NEWSLETTER

January-February 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.

COPD Caucus, CSPR Annual Conference, Pulmonary Fibrosis, Oxy-glasses, Normal Oxygen levels, Resistance devices, Early diagnosis of stroke & SAS test, Smokefree CA, Serevent

Happy Valentine's Day!

COPD CAUCUS

Do you remember back in June of 2003 we told you the exciting news about the **Congressional COPD Caucus** being planned by **Senator Mike Crapo (R. Idaho)**? He called pulmonary problems a national concern and was joined by **Senator Blanche Lincoln (D. Arkansas) and Rep. John Lewis (D. Georgia).** We hope that *your* senators and representatives will soon join this Caucus also. Perhaps you will be inspired to urge them again when you read the following news item from Washington reported by *John Leaman, editor of Respiratory News and Views.*

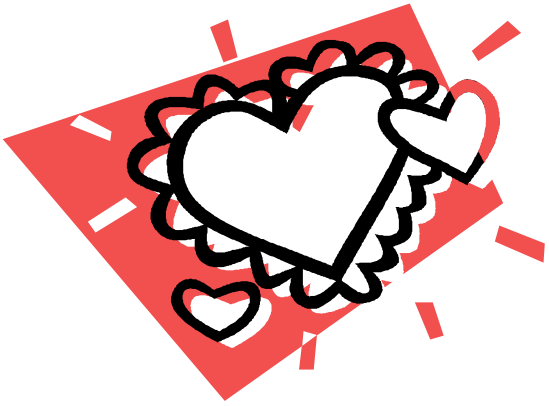
Senator Mike Crapo (R. Idaho) on January 19th asked **Michael Leavitt** to bring a new focus on pulmonary health issues if he is confirmed as the new **Health & Human Services Secretary**.

In confirmation hearings before the **Senate Finance Committee**, Senator Crapo declared "Chronic Obstructive Pulmonary Disease, or COPD, is the 4th leading cause of death in our nation. While statistics show improvement in other chronic health areas, pulmonary health continues to decline. Annual per capita expenditures for Medicare beneficiaries with COPD are two-and-one-half times higher than those without COPD. I want Secretary-designate Leavitt to bring an increased emphasis on COPD."

Mr. Leavitt told Senator Crapo he was already aware of Crapo's campaign to bring more attention and resources to COPD. He pledged that if confirmed he would make COPD issues a priority.

We will be following this carefully and keep you posted. It is nice to know that we have at least one friend in the Senate who is trying to raise awareness of this very important issue.

Senator Crapo gets our vote as the COPD valentine of the Year!



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THANKS FOR THE REMEMBERANCES!

A great many of you generously remembered PERF during the holiday season. We appreciate the donations received and also the good wishes from those of you unable to contribute at this time. Our thanks go to Gene Voohres and Dr. Paul Selecky for their donations for the Chair, along with Louis Rollino for the Chair in memory of Dorothy Rollino, L.B. Cane in memory of Dr. Seymour H. Cane, Ann Wentink, in honor of Mary Burns and Jim Wood in memory of Carlin Wood.

Mary Burns and the PEP Pioneers joined Allen Morita and his family in memorial donations for his mother, Sachiko Morita. Reta Long, Mary Burns and the PEP Pioneers also donated in memory of Dorothy Hall. These two ladies often helped prepare the newsletter for mailing. They were dear friends and will be sorely missed.

Thanks also to Kevin & Judy Hettich, Dr. David Lewis, Gladys Mollison, Keith Elledge, Joyce Bauman, Carol Smith, Rhodo J. Kelley, Carolyn & Gary Verhage, Robert Zerfing, Warren Mittelholz, Sam & Vicky Praw, Ted Von Goerlitz, William & Lucinda Wright, Rubye Richey, Keith Elledge, Joyce Bauman, Carol Smith and Rhodo J. Kelley,

Chris Garvey, RN, MPN of Seaton Medical Center made a donation in memory of. Michael Stulbarg, MD. Dr. Stulbarg was a national leader in research and compassion for persons with lung disease. He trained hundreds of residents, fellows, and students who have gone on to care for patients with lung disease around the country. All of us join Chris in condolences to his family.

Dr. Richard Casaburi and his lovely wife Mary showed where their hearts are. They made a very generous donation to their favorite charity and ours, PERF. No one knows better than the PERF Board members how carefully each cent is husbanded.

Alvin Grancell made a donation in honor of the 95th birthday of his brother Sherman. This gift to PERF will be used for the training of foreign scientists from countries needing assistance in learning more about the care of pulmonary patients. His brother and sister-in-law, Sherman & Sylvia Grancell, made an equally generous donation. Dr. Janos Porszasz also donated to this special cause.

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CSPR (The California Society for Pulmonary Rehabilitation) will hold their Pulmonary Rehabilitation 2005 World Conference in Oakland, CA at the Oakland Marriott City Center on April 21-22. For further information call Jim Barnett at 1-877-280-2777.

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We Get Mail!

Please remember that a newsletter is limited to general information. Only your physician can accurately diagnose and treat you.

Pulmonary Fibrosis

Gary writes: "*I have pulmonary fibrosis. About 3 weeks ago my breathing became very shallow and I was having trouble sleeping. I went to emergency and was told that my problem could be caused by an infection. I was put on antibiotics for 10 days. They put me on oxygen while I was in emergency and my oxygen level went from 94% to 97%. They later took an arterial blood sample and found it to be 94%. At no time was I given a stress test. Do I need oxygen at home?*"

Usually you have to have an oxygen saturation of less than 89% with exercise to be eligible for home oxygen. With pulmonary fibrosis oxygen levels may be quite adequate at rest, as yours were, but drop substantially with exercise. This is especially true if you have a pulmonary infection. If you are still having unusual shortness of breath with exercise you might ask your physician about testing your oxygen level during a 6-minute walk, even though they were normal at rest. Do remember that shortness of breath does not necessarily indicate the need for oxygen.

Gary also asks: *"In one of the articles on your web site they discussed the use of Tiotropium for COPD. Does it help pulmonary fibrosis? What is the difference between pulmonary fibrosis and COPD?"*

Unfortunately, tiotroprium bromide (Spiriva) has not been shown to be effective with pulmonary fibrosis.

COPD stands for chronic obstructive pulmonary disease, which usually includes emphysema, chronic bronchitis, and some severe chronic asthma. Pulmonary fibrosis is a restrictive disease. We'll go into this in greater detail at a later date since it is a question we often have and is of interest to many people. I'm glad you asked! Keep reading the Second Wind for information.

Oxy-glasses

Ann asks, *"What are Oxy-glasses?"*

Good question since we neglected to explain this in our last newsletter. Oxy-glasses are glasses with hollow frames and earpieces though which you can

thread oxygen tubing. The small amount of tubing that shows around the glass frame allows oxygen into the nares of the nose and is barely visible. Your eyeglass prescription can be used, or sunglasses, or plain glass if you don't need magnification. Dr. Petty often uses oxy-glasses during lectures and the audience not in the know is surprised to learn that he is actually receiving oxygen.

Normal Oxygen Level

Shirley was wondering *what a normal oxygen level should be in a 53 year old white male. Her husband just got diagnosed with COPD and his level was 90. She very concerned.*

That answer is a little more complicated than you might expect. It depends on the *altitude* where your test was taken and if it was done with an oximeter (a device clipped to the ear or finger) rather than an arterial blood gas (with blood drawn from the wrist). It also makes a difference if he was sitting at rest for 20 minutes before the test or if it was taken at the end of a period of exercise. There are other factors that can affect the accuracy of an oximetry reading, the most common of which are the circulation of blood to the finger with the oximeter, or smoking before the test. The carbon monoxide in the smoke combines with the oxygen in the blood. This results in an oximeter reading that falsely overestimates the amount of oxygen carried in the blood. It is also important to know if this was a routine test or taken while he was ill with a lung infection, such as pneumonia.

All that being taken into consideration, the normal oxygen saturation of a person at sea level would be about 95-98% saturation, so his reading may be somewhat low (though not apparently low enough to require chronic oxygen therapy) . There are many things that can be done to help your husband improve his oxygenation. The physician will probably give him inhalers to open up his airways. An infection will be treated with antibiotics. If he is very overweight it prevents the lungs from expanding properly and loosing weight will help. If he has chronic bronchitis it can be helped with various medications and cough control techniques. In pulmonary rehab classes we find a dramatic decrease in sputum production as patients increase their daily activity level.

If his oxygen saturation was taken at rest, it may be repeated and taken after a six-minute walk. Oxygen is not prescribed until the saturation is down to 88%, and occasionally 89%. If he has acute infection saturation will be checked again when he has fully recovered, usually about 3 months. As you can see there are many things to be considered. I'd urge you to ask your physician about a referral to a pulmonary rehab program if there are any in your area. They will help both of you understand his condition and get started on an exercise-reconditioning program. Our web site also has a lot of helpful information. Don't forget to check the archived newsletters. There is a *lot* that can be done to help your husband improve! It is wonderful that he has your support and encouragement!

Resistance Devices

Dan asks: *Is there any merit to devices to which you can set a resistance to exhalation or exhalation and inhalation (i.e. Powerbreath, PowerLung, Expand a Lung). I'm pretty fit and am breathing fairly well except when I have a bronchial flare-up. I've been doing PLB with good results though I was probably blowing too hard judging from your information and the exercise book I just received by Vijal Sharma, Ph.D. (he says blow out like your cooling soup in a spoon or causing a candle flame to flicker).*

It seems logical that lungs and diaphragm and other muscles would be strengthened if they had to work against greater resistance. I've simulated the action of the above

devices by using the flexible end of my nebulizer and breathing in and out while partially blocking the end. *Might it be doing some good?*

As you may know, the medical professionals in our Foundation are especially interested in breathing techniques and have been involved in research about its effectiveness. We had a lot of fun with some of the studies we did with pursed lip breathing. Much research has been done on resistive breathing devices and exercises which might strengthen the diagram. They seem helpful for people confined to bed or with serious physical limitations. It doesn't sound as if you are in that category. Most research indicates it probably would be of limited value for someone like you. To explain, it is sort of like telling your mailman to walk 30 minutes three times a week when he gets off work. It isn't going to hurt him, it may help a little, but it is not of great value. (Unless he is sitting in a truck all day!)

You are right not to concentrate on breathing out too hard. It can actually lower the oxygen level of your blood if you do it too forcefully. But please don't worry about it since it is nothing you would do without a great deal of concentration. Besides, it would make you light headed! Congratulations on continuing to exercise. It is one of the best things you can do to improve your health.

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Dr. Petty sent us the following valuable information.

Early Diagnosis of Stroke

This is an important and simple test that we can all teach our families and friends which may help in the early diagnosis / therapy for brain stroke. Failure in any part of this test demands that the patient receive medical attention immediately. Wasted time paralyzes and kills!

This is the Cincinnati Prehospital Stroke Scale given a different name in the name of

KISS (Keep it Short and Simple):

The SAS test

Smile-Arms-Sentence

Symptoms of a stroke are difficult to identify. Unfortunately, the lack of awareness can spell disaster. The stroke victim may suffer brain damage when people nearby fail to recognize the symptoms of a stroke. Now doctors say a bystander can recognize a stroke by asking three simple questions:

Ask the individual to smile.

Ask him or her to raise both arms.

Ask the person to speak a simple sentence.

***If he or she has trouble with any of these tasks, call 9-1-1 immediately and describe the symptoms to the dispatcher*.**

After discovering that a group of non-medical volunteers could identify facial weakness, arm weakness and speech problems, researchers urged the general public to learn the three questions. They presented their conclusions at the American Stroke Association's annual meeting last February. Widespread use of this test could result in a prompt diagnosis and treatment of the stroke and prevent possible brain damage.

A cardiologist stated that if everyone who gets this message tells this to10 people, you can bet at least one life will be saved. Tell as many people as possible about this. It could save their lives!

(This SAS test has already resulted in the prompt treatment and recovery of a good friend of this editor. Pass it on!)

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Smokefree California

It has been 15 years since California launched its tobacco control program and ten years since the passage of an unprecedented statewide smokefree workplace law. Do you remember the gloom, doom and dire predictions of all the protestors?

Well, guess what? Data just released shows that *90% of Californians now approve of the smokefree workplace law!*

The new figures from the 2004 California Student Tobacco Survey also show that smoking was down to 13.2% of high school students in 2004. It was 16% in 2002 and 21.6% in 2000. That is progress!

In addition to this new data, 52% of smokers who quit in the past 10 years said that these smokefree public places had made it easier.

But what about all those smokers who haven't quit? They say this tough law has made it easier to cut down on the number they still puff. Even more surprising, people who moved to California since the law went into effect overwhelmingly support the smokefree workplace law. And that includes the half that was still smoking! They agreed that smoking should be prohibited in the outdoor dining areas of restaurants.
We hope that those of you who live in parts of the country where smoking is still allowed in restaurants and the workplace will pass this recent survey around.

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SEREVENT

Do you remember the series on Herbal Medications written by **Dr. Herb Webb**? He is Medical Director of the San Pedro Peninsula Hospital Pulmonary Medicine Department as well as the Pulmonary Rehab program. We would like to thank him and **Editor Kris Brust, RN** for allowing us to share the following with our readers. It is a reprint from their newsletter, which we thought, would be of interest to all of you, also. The following is a question from one of their patients, and the answer given by Dr. Webb.

'My neighbor read on the Internet that a new study says Serevent is dangerous – holy smoke, I've been using it for years!'

Dr. Webb replies: In my opinion and experience --- and other information in the medical literature agrees – salmeterol (Serevent, Advair discus) is one of the safest medications ever prescribed.

In 1996, to assess the safety of regular use of certain types of inhalers in the treatment of asthma, the drug company GlaxoSmithKline commissioned a large study in cooperation with the FDA. Study findings were inconclusive, but the end analysis attributed the usage of salmeterol (Serevent) in causing untoward respiratory events in less than 1% of 25,858 study subjects. The study was abandoned, but GSK sent a lawyerly 2003 communication to all MDs saying that although the data in the study was inconclusive, doctors should remember to prescribe Serevent appropriately and educate their patients in correct usage. Of course, when news of this

unpublished and inconclusive study hit the Internet, the office phones started ringing off the hook. Thank you for calling, by the way. I recommend that patients ALWAYS discuss such information with their physicians before panicking or stopping medication.

"Untoward respiratory events" means worsening asthma that is potentially serious, even deadly, and requires hospitalization. This finding is in dramatic contrast to what all previous studies have shown, and further analysis shows that the preliminary conclusion –-- that the use of Serevent is associated with untoward respiratory outcomes in asthmatics –-- is incorrect.

First, the GSK study was done in younger asthmatics, and not in patients with emphysema or chronic bronchitis, so in evaluating results, the findings don't really apply to our Pulmonary Rehab population. Secondly, the article clearly states that the asthmatic patients in the study who had bad outcomes were not being treated correctly for their asthma in the first place! These patients were not, for the most part, being given inhaled corticosteroids, basic to the treatment of asthma. Inhaled corticosteroids decrease the swelling and inflammation that we know is one of the underlying causes of asthma symptoms, and since these patients were not being treated appropriately, it could reasonably be expected that they would develop untoward events. So, the worsening of the asthma symptoms had very little to do with the use of Serevent, and a lot to do with the absence of regular anti-inflammatory meds. The study also states that the patients who had the most untoward events not only were under treated, but also had the worst lung disease: severely compromised pulmonary function tests and histories of a high number of emergency room visits and ICU stays for asthma.

Interestingly, some of the patients in the study were adequately treated. In the sub-population of patients actually receiving inhaled corticosteroids, there was no difference in untoward events between the asthmatics getting Serevent versus the group not getting Serevent. In other words, as we've always know. Serevent is an important addition in the arsenal against asthma, but it can't do the job alone. Hence the GSK communiqué.

Serevent is extremely efficacious in the treatment of asthma and COPD. Along other lines, I make reference to a study in the New England Journal of Medicine from May 2002. This study was not done on lung disease patients, but was looking at the safety of salmeterol from a cardiovascular standpoint. Patients were given a whopping 5 breaths – the usual dose is 2 – and those studied did NOT show increased heart rate or blood pressure.

Patients must be aware that Serevent and Advair discus are not rescue inhalers --- they take too long to work to help you if you are suddenly experiencing extreme shortness of breath. Salmeterol has a slow onset of action. COPD and asthmatic patients must always have access to a short acting bronchodilator (rescue inhalers: Ventolin, albuterol, Combivent). But as the study showed, asthma patients often get out of control if they rely totally on rescue drugs; they need medications that address the inflammatory aspect of their disease. Last, all patients should make sure they understand why they are taking their meds, and call their MD if they have questions.

In summary, the worsening of the asthma symptoms had very little to do with the use of Serevent, and a lot to do with the absence of regular anti-inflammatory medication.

Again, our thanks to Dr. Webb for this timely article.

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Hope you had a sweet Valentine's Day!

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Senior Moderator

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January 2005

Dear Friends:

Dogs Don't Sweat

Have you ever noticed that dogs don't sweat no matter how heavy their coat may be? The reason is that they don't have any sweat glands. The only way dogs can lose heat is by panting. Thus they breathe at an extremely rapidly rate to lose heat through evaporation from their tongue and air passages. In this process they also lose water. Your dog must have plenty of water during hot days or while exercising.

Dogs are born hunters. They can chase their prey for long distances, but they finally get tired and have to rest and pant. Dogs may be descendants of wolves. Early wolves learned to organize into community groups and, in fact, may well have helped primitive man in achieving some social organization.

Also "dogs don't sweat the small stuff." Your dog will forever be your loyal companion. This happens in spite of your unintentional failings, such as, at times, lack of enough attention, proper food and shelter. Dogs are always forgiving. Dogs love you unconditionally!

Most dog owners share their love equally with their dogs, which they often regard as a spiritual animal very much like a brother or even child. Dogs are to be admired as lifelong companions. Dogs are, indeed, man's best friend.

I'll be in touch next month. Happy New Year!

Your friend,

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February 2005

Dear Friends:

"IS THE STRUGGLE FOR RECOVERY WORTH IT?"

This letter begins with a somewhat rhetorical, yet philosophical, question. I sometimes have viewed the pathway of critical illness like entering a dark tunnel. When one enters an ancient cave or mineshaft, one does not know if it branches, reaches a dead end, follows a maze where one could get lost, or emerges with light at the other end. Giving up the light of day to enter an unconscious state of anesthesia has always both interested and worried me. Long ago I asked the anesthesiologist to quit telling me "Well, here we go." I can remember the first stage of general anesthesia where I dropped into a black hole not knowing where it ended or what would follow. Upon awakening, I had the answer that more life lay ahead. So it is with many people who struggle to battle both acute and chronic illnesses.

There are times when the battle must be halted and a détente declared. I called this a détente with death.

There will be a time, guaranteed, for all of us when the struggle to survive is not only futile, but meaningless. I believe the journey to find one's spirituality takes final hold at this point.

Those of us who have suffered serious and critical illness quite naturally have had to endure suffering in order to reach our goal of survival. This may be painful, frustrating, depressing, fraught with periods of exhilaration only to be followed with the crush of despair. All I can say is that the struggle for survival is worth it until the end of life is at hand.

I'll be in touch next month.

Your friend,

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PS. I wrote this a few months ago. The struggle was worth it as I enjoy this Valentine's Day. Remember the old song, "Every Day Should be Valentine's Day!"