Second Wind
NEWSLETTER

March 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, or 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.

Key Words: Herbert Webb, MD "Studying Herbal Remedies" Part I. Richard Effros, MD, "Treatment of Chronic Lung Disease", Ron Peterson and exercise.

We receive letters and email from around the world, and know that many of these questions, and their answers, are of interest to many of our readers. In the future, we will print several of these every month, changing names and some of the details, to insure privacy for those who wish it.

We received some letters recently that fit right in with our next article. A very nice gentleman writes that his doctors give him no hope of improving his emphysema or getting off oxygen. He has met a therapist who has promised to cure him in 3 months with an extract of herbs. He only has to take one drop in milk 3 times a day, stay on organic foods, and do a few simple exercises. He wanted to have our opinion.

I'm afraid we can't be as positive as his therapist, but we don't blame anyone for being tempted by a promise like this. If you do have emphysema a variety of COPD, as your doctors have told you, there is *no way* that anyone can legitimately guarantee you a complete recovery. We can understand how desperate you are to

get better but please be *very* cautious about following the advice of anyone who promises a complete cure. If your therapist *did* have a miracle herb, we can assure you that every physician in the world would be prescribing it for our pulmonary patients. They want you to get better! And your therapist would be a multi-millionaire when he sold the secret of his herbs to a pharmaceutical company. Please be careful! We have found some of these medications to contain stimulants, steroids and other ingredients when we had them analyzed at a university pharmacy; these ingredients can cause serious problems. It would be best for you to discuss this with your pulmonologist who is in a better position to evaluate what you are getting than we are. The exercises are probably good for you, organic foods certainly can't hurt, and you are taking such a small amount of the herb that you doctor may not object to you continuing as long as he can monitor your condition. And this is a great time to introduce our next guest, who will give you a lot more information on this subject.

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 Hospital Pulmonary Medicine Department and their Pulmonary Rehabilitation program.** He wrote this article for their Better Breathers' Club newsletter. With their gracious permission, we share it with you.

HERB on HERBALS

Studying Herbal Remedies

Part one of a four part series

Let me start by saying that I am definitely not an expert on herbal remedies. My perspective is that of a skeptical, professional, conservative, mainstream pulmonary physician, and my watchwords are "Prove it to me that 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 can be complimentary rather than an alternative to conventional medications.

We can't ignore that herbals, megavitamins and nutritional supplements are a major issue of our time. In 1999, United States consumers spent over 14 billion dollars on these items. Over 500 different herbs are marketed, and 200 of them are relatively common. The top ten account for approximately 50% of herb sales. These include echinacea, garlic, ginseng, gingko biloba, golden seal, ma-huang, saw palmetto, and now glucosamine and chondroitin sulfate. Half our population between age 35 and 50 has tried alternative measures of some type. There is now even a PDR (Physicians' Desk Reference) for herbal medicines.

So, marketing forces bombard us every day with information, both good and bad, about these agents. The medical profession is trying to respond to a clear-cut need in the public's eye to be more caring, more soothing, and more open to the idea of herbals and supplements. Fifty percent of United States medical schools now have alternative medicine courses, and the FDA is

trying to respond to this issue as well. The genie has definitely been let out of the bottle and it won't go back in, so it is prudent to learn quickly for our patients' sakes as well as our own.

Why do people have such zeal to take herbals and megavitamins? The idea of an easy to obtain and easy to take pill is appealing. We Americans also have a strong urge for self-control and controlling one's own destiny. Also, the emphasis on prevention is enticing. Many believe "olde is good"----it was good enough for Grandma, so it's good enough for me! And others think that "natural is safe". (But, as we shall see, there isn't any more reason to think that natural is safe than that "synthetic is not safe". More on this later.)

Many physicians zealously argue AGAINST all herbals, and many citizens manifest religious fervor FOR herbals, rejecting all prescription medications. These two extremes seem just that to me—extreme. We need less polemic and more science.

In defense of doctors, I must remind you that it is extremely difficult to keep current in your own medical specialty nowadays. There are only 24 hours in a day, and the information explosion in our own fields is demanding. Herbal remedies are another branch of healing entirely, one in which few United States physicians have been trained, and even if a doctor is inclined to research, finding reliable scientific evaluation of herbals to study is very difficult. Herbs, of course, do have action on the human body, which means they have side effects and toxicities and drug interactions and even interactions with other herbs. It is important to remember that herbals contain active ingredients, chemicals like the biochemicals synthesized by pharmaceutical companies. You can't just dismiss these preparations as harmless or placebos (as some physicians unwisely do!). Herbs are potentially dangerous, as well as potentially therapeutic. So, I think you should think of herbals and nutritional supplements as drugs, just like FDA-approved pharmaceuticals, with side effects, toxicities and drug interactions.

So, if there are certain similarities between herbal remedies, dietary supplements and FDA approved pharmaceuticals, what are the differences? A basic difference between herbal remedies and standard drugs is that the Food and Drug Administration controls only the latter. This includes testing, safety controls, manufacturing, standardization, and a formal system to report adverse reactions once the drug is out there. We have all heard side effect stories and read inserts listing precautions for standard Western-type medications, so everyone is quite aware of side effects, toxicity and interaction issues with traditional therapies. If herbal preparations were in fact controlled by the FDA, my expectation is that we would hear about side effects and herb-to-drug interactions just like we do with FDA-controlled and synthesized medications. We haven't heard much about problems with herbals because there's no way to report adverse reactions, and no regulatory body to report them to.

Another problem surrounding the current state of herbal use is a disturbing lack of scientific studies. Unreliable information is more dangerous than no information at all. Reliable scientific studies of herbal preparations are scant, and very few studies meet the scientific scrutiny that is required for all FDA approved medications. So, what do I---and the Food and Drug Administration---consider a solid, worthwhile scientific study?

First, a study should answer a specific question, like "Does drug Z decrease strokes in men over 60?" or "does herb X lower diastolic blood pressure in women over 50?" It should be a double blind, randomized, placebo-controlled design. A placebo, of course, is a "sugar pill": that doesn't have any effects. The real deal and the placebos are identical in appearance and are assigned tracking numbers, so they can be given out at random. This way, neither patient nor researcher knows who's getting the placebo, which eliminates emotions and prejudices from coloring the results. Make no mistake; the placebo effect is very real. Expectation that something is going to help you is a very strong factor and can actually provide positive results. In all asthma studies done with placebos as a control, there is a dramatic placebo effect---in other words, people who took fake asthma medication reported breathing better. In a recent study of a baldness remedy, 86% of the men taking the therapeutic agent claimed hair growth, but so did 42% of those taking the placebo!

A good study should also have as many participants as possible---the more the better. The people in the study should be able to tell researchers their subjective opinions on whether their pill helped or not. Although subjective feelings are important, the researchers should also be able to measure their study question objectively, which in the case of the blood pressure study, would be easy to do. (You'd think it would also be fairly easy to see if a remedy grew hair, but apparently not.) Last, but certainly not least, the study should he reviewed by experts in the field before it is published.

Now, I can read medical scientific journals by the thousands with articles on drugs meeting the above criteria, but there are virtually no such sources specifically directed at herbals and supplementals.

The next question is, if there aren't any scientific studies for my doctor to read, then, where can I get decent consumer information? The **Harvard Medical School Health Letter** is the best, and the **Mayo Clinic, National Jewish Hospital** and **Johns Hopkins** also have good information for you. These general health letters do contain information about herbals, vitamins and supplements amongst their many other contents. The **Nutrition Action Health Letter** is excellent, and concentrates on food, nutrition, supplements and herbs.

Harvard Medical School Health Letter
79 Gardener Street
Cambridge, MA 02138
(617) 495-1000
Mayo Clinic Health Letter
Subscriptions: PO Box 53889
Boulder, CO 80322-3889

Generally speaking, if someone wants to sell you something, you should be *very wary*. Commercial advertisements, material you receive in the mail, promotions, sales pitches, and Internet sites of any commercial nature are poor sources of accurate information. You can also categorically reject panaceas which claim to cure your insomnia, improve your memory, promote weight loss or weight gain, increase energy, reverse your baldness, cure you impotence, soothe you arthritis, decrease your shortness of breath and prevent a heart attack as well. It's true that prescription medica-tions are now advertised directly to the public, but you still must obtain them through physicians. The fact that your doctor, who knows your condition, allergies, and other mediations, has to be consulted for a new prescription is a safety feature, not a bother!

We hope that you liked this article as much as we did. Part 2 will be in next month's Second Wind.

PERF again thanks John Boynton for his quarterly donation to the Chair. The Women's Fellowship of the Neighborhood Church in Palos Verdes Estates, CA made a donation from the proceeds of their Annual Yule Parlor Parade. (If you are ever in this area in early December this is an event not to be missed!) Thanks also to Jim & Iris Fraser and Denise Giambalvo RN, MN for their donations. Wanna Tolliver and Paul Donatoni each made a memorial donation in memory of Jerry Donatoni. Jim Wood made a donation in memory of Evelyn Gould and of his wife, Carlin.

TIME IS RUNNING OUT but there is still time to join us at the California Society for Pulmonary Rehabilitation (CSPR) annual meeting April 22-23 at the Long Beach Hilton, in Long Beach, California. This is an inexpensive way to get 12 CEU's, or CME's, enjoy all the fine lectures during the day, and network in the evening with this friendly group dedicated to pulmonary rehab. Call Jim Barnett toll free at **(877) 280-2777 or c**heck the PERF Website at www.perf2ndwind.org for the brochure, "Keeping It Alive"

Many thanks to Barbara Butler for many nice things she said about our newsletter on her phone message. It meant a lot to us, Barb. Thanks!

Harbor-UCLA REI (Research & Education Institute) Rehabilitation Clinical Trials Center (*Whew! What a mouthful*!) sponsors a monthly "*Brown-Bag Luncheon Meeting*" on the 4th Friday of every month. Folks bring their own lunch while drinks and desert are provided. With so many well-known docs and researchers on campus, you can be sure this monthly meeting will be of exceptional caliber. The guest speaker in February was **Richard Effros, M.D., a member of the Pulmonary Faculty at Harbor-UCLA** whose topic was "**New Directions in the Treatment of Chronic Lung Disease".** We are pleased to offer you a few of the highlights of this talk.

Dr. Effros caught everyone's attention by explaining that he has had a form of obstructive lung disease since the age of 4. He had severe asthma, possibly triggered by the smoking of his mother. He discussed the differences, similarities, and overlap of symptoms between asthma and emphysema. Asthma by definition is

reversible while the inflammation of COPD is not. However, *sometimes* asthma also can become less reversible with some fixed obstruction, and thus turn into COPD.
Instead of immediately discussing the latest medications and trends, Dr. Effros brought things into perspective by regaling the audience with tales of *old* remedies. He referred us back to Dickens, rather than medical texts, for some of the earliest descriptions of disease. Dickens, while not a physician, was a trained observer. In fact, in Pickwick Papers, his description of the obese boy with a huge belly who was always falling asleep standing up, is the textbook picture of a type of sleep apnea. Even today, naming this the 'Pickwickian syndrome' honors Dickens' observat-ions.

In those days, strong coffee was the only treatment for asthma. Coffee contains a substance similar to theophylline, which is still used to treat asthma. Back in 1850, and for many years later, asthmatic patients relied on "asthma powders". They were created by soaking paper in a mixture of belladonna and potassium nitrate, burning them, and inhaling the smoke to open the airways. Asthmador cigarettes were smoked to relieve asthma. That's right. Medicated cigarettes were encouraged for those with respiratory distress! They contained belladonna, which is related to today's Atrovent.

Dr. Effros gave us many other examples, commenting that many of today's medicines are derived from much older drugs. For example, the Chinese used an herb called 'ma huang' for more than 1000 years to make a tea, which was used to treat asthma. Ephedrine is the active ingredient in ma huang, and it was very popular as a medication for asthma for many years in a tablet form called "Tedral." It is also the active ingredient in the weight loss drug called "Ephedra," which was recently taken off the market because of potentially fatal cardiovascular reactions.

Adrenalin injections (related to today's Albuterol) were first used in the first half of the 20th century) when it was the only medication available in emergency rooms for relief of severe respiratory distress. In spite of the potential of severe side effects, adrenalin is sometimes used even today, with great caution, to save the lives of those in anaphylactic shock (a severe allergic reaction) because of the immediate response and relief of symptoms that it can provide.

Dr Effros, who was involved with industrial medicine, was intrigued by the fact that the damage caused by inhaling smoke from *cigarettes* is so different from the damage done to the lungs by other inhaled pollutants. Cigarette smoke causes COPD or *obstructive* disease. Inhaling pollutants from industrial products can cause *scarring* in the lung, which results in *restrictive diseases* such as pulmonary fibrosis, or pneumoconiosis, seen in coal miners. In restrictive disease, the lung gets *smaller,* constricted by scarring, and it is difficult to get air ***into*** the lungs.

Cigarette smoke destroys the elasticity of the lung and its ability to spring back, making it difficult to get air ***out*** of the lungs. The lung *enlarges* because of destruction and

air trapping in the alveoli. We use the belly muscles to press the diaphragm up to squeeze air out, BUT, if done with too much force, this can cause *additional* compression of the airways and obstruction. (Do you remember being told in rehab not to work too hard to force your breathing? Now you know why.) It is somewhat reassuring to know that we normally have two to three times as much lung as we need. This is why someone can have one whole lung removed and still remain active.

Lung damage can be documented with the **PFT (pulmonary function test)**, which compares your lung function to the average for your age, height, and sex. The **FEV_1**, which is an important part of the PFT, is the amount of air you can blow out of your lungs in one second. That is that number that Dr. Petty keeps telling everyone that they should know.

Did you know that the inside of your lungs is normally *sterile*? How is that possible when it is continually exposed to organisms inhaled from the environment and the organisms that normally live in the mouth? Amazing, isn't it? Dr. Effros explained that the lungs secrete about ½ quart of fluid each day, which continually washes out any organisms which land on the airway surfaces. This is referred to as the "mucociliary elevator." We swallow this fluid without being aware of it. Cilia, tiny hair like projections inside the lining of the lungs, help this process of sweeping debris out of the lung. Cigarette smoking paralyses and damages the cilia and interferes with the flow of fluid from the lungs. Mucus accumulates in the airways, the lungs are no longer sterile, and infections can start to take place with organisms that are always present in the mouth
In addition to the mucociliary elevator, about ½ quart of water is lost from the lungs each day by evaporation as *water vapor*, which keeps the surfaces of the lungs moist. This is the moisture that causes the "steam" you see when you exhale outside on a cold day.

In response to the irritation caused by cigarette smoke, and the presence of bacteria in the airways, inflammatory cells enter the airways. Although these cells may help prevent the spread of infections, they also release enzymes, which can destroy the elastic tissue of the lungs, thereby contributing to the development of emphysema. This is particularly serious in patients who lack ?–1–trypsin inhibitor, a protein that normally inhibits the action of these enzymes

The exact role of steroids, which are used to reduce inflammation in COPD, remains quite controversial at this time. Many pulmonologists in the United States feel that steroids are helpful only during an acute exacerbation. Studies have shown that they do not prolong life. As you know, taking prednisone tablets over a long period of time can cause many complications. Even inhaled steroids can affect the musculature of the vocal cords and sometimes cause fungal infections in the mouth, though these problems are usually mild and readily treatable.

In answer to questions from the audience Dr. Effros commented that bronchiectasis (an abnormal dilation of the bronchi which promotes

recurrent infections) was much more common and serious before the days of antibiotics. Fewer children now get whooping cough, measles or untreated pneumonia, which were the major causes of this illness. It is also much easier to diagnose bronchiectasis now that we have CT scans, making it unnecessary to inject dyes into the lungs. He also commented on the possibility that some cases of bronchiectasis in adults may actually be a mild form of undiagnosed cystic fibrosis. A **sweat salt test** should be done to rule this out since so much more can now be done to help this condition.

He ended with a final tidbit of fascinating information. We are born without true alveoli! Alveoli start developing at birth and continue to grow until about the age of seven. Children with asthma are stimulated to grow extra alveoli and can compensate by developing "supernormal lungs" as do babies born at high altitudes with lower oxygen levels.

Everyone thanked Dr. Effros for a fascinating lecture that helped us get a different perspective on how the past evolves into the present and on to the future. If you live in the Torrance area and are interested in attending one of these meetings call **(310) 222-8276** for information and directions. For those of you who live a bit too far to manage the drive, we promise to keep writing up some of these talks. And yes, Dr. Effros promised to come back soon. We'll look forward to it!

Ron Peterson has been corresponding with us for *years* and is one person who *wants* his name to get out there. He's not shy! Ron had a lung transplant 3 years ago. He emailed us that he has just completed his 254th consecutive day of walking at least 60 minutes a day and feels great. He plans to do this until he is "deceased since they can't bury you if you are walking." He is now 59 but plans to live until he is 150 so that he gets the record for longevity with a lung transplant. Way to go, Ron! And if you think you need a lung transplant to walk an hour a day you should know that Ron achieved that goal while he was waiting for a lung on the transplant list. When he first wrote to us he could only walk a few minutes at a time, but he persevered. Check the PERF Website on "*How to Start an Exercise Program*" to see what worked for him. He is now a true believer in the value of exercise. Ron was discharged on the 3rd day post op; he was told that no one ever bounced back from a lung transplant as fast as he did. We believe it! In his spare time, Ron produces inspirational videos to help teenagers quit smoking or, better yet, never start. He is one special guy. If you would like more information, contact him at ron@preventionvideo.org.

"Life is not a journey to the grave with the intention of arriving safely in a pretty and well-preserved body. But, rather, it should be a long skid in broadside, thoroughly used up, totally worn out, and loudly proclaiming -- 'WOW!! What a Ride!!!'"

Snowdrift Pulmonary Conference

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Senior Moderator

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Dear Friends: March 2004

Greater Liberation with Portable Oxygen

Most patients who need oxygen in their daily lives would like to be able to travel more. Travel by car is possible with a growing number of lightweight concentrators, which are powered directly from the car battery through the old cigarette lighter. These nine-pound concentrators can be easily carried into a motel or hotel at night. They are very soon to be approved for air travel. The battery on the first of these concentrators lasts only about 45 minutes. The newer devices have a nearly three-hour battery life. The battery is always being charged, when external electricity is used.

This is a vast improvement over old-fashioned cylinders, which are heavy, or lighter tanks which last only a few hours. And you still need a concentrator for nighttime use.

For patients who use the lightweight portable liquid systems such as Helios or Spirit, a filling source is needed. The CAIRE Liberator-10 liquid reservoir is just the right device. It will fit in the back seat of the car for travel and is the source of refills. It weighs about 50 pounds full, and lasts about a week. The Liberator-10 is manufactured by CAIRE of Minneapolis and is available via most suppliers, such as Apria, Lincare and CAIRE. The Apria Company also provides a booklet with helpful information regarding location of their outlets for needed refills along the way.

Liquid portable systems are the most versatile and practical portable oxygen systems and are ideal for long-term travel, i.e., a week or more with refills that are available across the USA.

So, things are getting a lot better with travel. Be liberated and visit family or friends. Or just go on a nice trip and take your time.

I'll be in touch next month.
Your friend,

Thomas L. Petty MD
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President, Snowdrift Pulmonary Conference