Second Wind NEWSLETTER

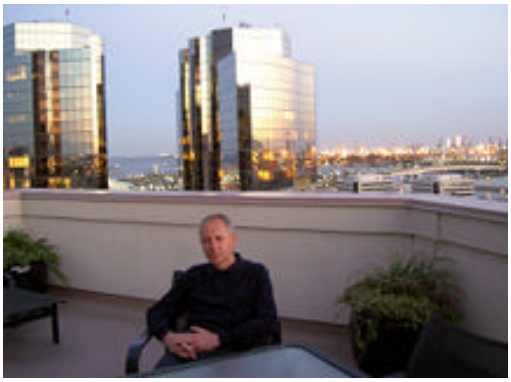
May 2004

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: Pulmonary rehabilitation in Norway and Russia, Hungary and Japan. Nonin oximeter, Spiriva, Herb on Herbals Part 3: Misguided Logic.

A few weeks ago, we had the privilege of hosting some wonderful guests from Norway and Russia at our annual CSPR (California Society for Pulmonary Rehabilitation) meeting in Long Beach, CA. **Dr. Audhild**

Olga Baranova, MD, Audhild Hjalmarsen, MD and Elmira Zilber, MD at the CSPR Meeting in Long Beach



Vladimir Kozlov

Hjalmarsen of Tromsö, Norway is a longtime friend who has visited here before. She asked if she could bring some colleagues from Russian to help them learn more about pulmonary rehab. Joining her for a 10 day visit were **Drs. Elmira Zilber of Karelia, Russia (600 kilometers north of St. Petersburg) and Olga Baranova of St. Petersburg**. They were accompanied by the very charming **Vladimir Kozlov**, who helped with the translations.

During their stay, they visited various hospitals including **Harbor-UCLA, Long Beach Memorial Medical Center and Citrus Valley Medical Center.** We'd like to thank the administrations and pulmonary rehab staff and patients at these hospitals. We'd also like to thank **Dr. Tom Storer of El Camino Community College** and the patients in his wonderful maintenance program. They all gave so graciously of their time. We can assure you that it was appreciated! **Dr. David Sachs of the Smoking Cessation Research Institute in Palo Alto** spent a whole day giving them the latest information on handling the chronic disease of smoking. To have an internationally renowned busy physician like Dr. Sachs give them a day of his valuable time was truly remarkable and much appreciated. He gave them some new insights into the smoking problem and how to control it. While smoking is a major problem in Norway, it is much worse in Russia, where 80% of the men still smoke. Participation of our guests in our CSPR seminar was one of the highlights of the trip for these physicians as well as for the other attendees. In two sessions, each participant first told us a little about pulmonary medicine and rehab in their respective countries and later answered questions from the curious audience.

Dr. Hjalmarsen impressed us with slides of her pulmonary rehab and maintenance programs in Norway. Tromsö is a lovely University town 600 miles above the Artic Circle. Because of the Gulf Stream, she describes the climate of Tromsö as "mild". A relative term, my dear readers! You are more apt to find polar bears than palm trees should you have the pleasure of visiting. We can't find our picture of a patient herding reindeer with his portable O_2, but here is a picture of one of their rehab oxygen patients riding his snowmobile. Another minor problem, she told us, is that for 2 months every year they *never*

Heated pool in Tromsö used for rehabilitation.

see the sun above the horizon. However, Tromsö makes up for it in the summer when the sun is visible 24 hours a day for two months! Would you like to have her tell us more details about life in the far North some day?

Dr. Hjalmarsen's programs can successfully compete with the best of any program in the States. There is even a swimming pool; indoors and *heated*, spoiling our vision of hardy Norwegians breaking the ice for a daily dip. Maintenance programs are part of rehab and, without cost, include 3 sessions a week in well-appointed gyms. All patients meeting standard guidelines of desaturation, and need for exercise, are put on portable liquid oxygen. National health care pays for all of this, plus medications, without any charge to the patient. Just recently, however, the Norwegian government has cut back on liquid oxygen payment so hospitals have to assume the cost. Even so, do you wish we also had such high quality health care, free to everyone? The Norwegian health care system ranks as one of the best in the world *but* there is a *small* catch. *Income taxes are at least 50% of income*. I don't know about Norway, but in *Sweden*, this rate can go up to *90%* for high-income people. Do the rock stars and baseball players complain? No, they move someplace where they don't pay such high taxes. I've got a feeling that would also happen here in the States should we increase our taxes this much.

Our two Russian physicians fascinated us with a glimpse of their country during the first session on pulmonary rehab and later when answering questions from the audience. Dr. Elmira Zilber started by telling us that it is winter 6 months of the year in Karelia. Long Beach was in the middle of a 96° heat wave so that instantly caught everyone's attention. Her hospital in Karelia is starting the first rehab of pulmonary patients in Russia with the help of Dr. Hjalmarsen and the Norwegian government. They have begun with breathing exercises, lectures, and proper use of inhalers and inspiratory muscle trainers. Life in Russia is in stark contrast to that of neighboring Norway. For many, many years, most of the wealth and the efforts of this vast country seem to have been devoted to the military. Infrastructure, and things like public health and hospitals, received scant attention and even less financing. Do you complain about the food you get when in the hospital? There is nothing to complain about in Russia since no food is provided to patients. Families are responsible for bringing in meals. No family? That presents a problem, though they assured me that something was worked out. All medications are purchased at the pharmacy without a prescription, but there is sometimes a problem with quality control or watering down, of medications. As is typical in most countries there are no respiratory therapists. Physical therapists, as we know them, do not work in hospitals either. There are very few nurses and no nurses' aides. Dr. Baranova told us that in one 640 bed building in her huge hospital there were only 34 nurses. That got the attention of her medical audience! Their nurses apparently don't seem to have the educational background that we have in the states, and definitely have

different job descriptions. So, who takes care of the patients? The physicians-in-training do most of the other work! These doctors are mostly women. Very few men go into medicine these days and it is easy to see why. Do you grumble about having to use oxygen when you go out in public? Russian patients don't have that problem. As in most Eastern Europe, there is no portable oxygen. In fact, there is no oxygen at all, even in the hospitals. If you are put on a ventilator, you will still be on room air, because even then oxygen is not available. The number one cause of death in Russia is pneumonia. The average age of death for a man is 57 years.

Dr. Baranova is the leading Russian expert on restrictive diseases. Russia seems to have many more patients and problems than we do because of air pollution and poor working conditions in factories and mines. Smoking doesn't help the situation. Dr. Baranova is hoping to start some form of rehab in St. Petersburg. She told us that one of their professors had been giving lectures to respiratory patients. How large was their class? Their class in St. Petersburg was an auditorium of 500 people……who were allowed to smoke in class. This shows how eager these COPD patients must be for help. I'm sure many of you can empathize.

Hospital care in Russia is paid for by the government, as are hospital workers. Physicians make $200 a month. Nurses make $100. (Gasps from the audience.) This is apparently no more than a factory worker makes and is difficult to subsist on. The problem is that the government just doesn't have any money to pay for this care. You may think that the good news is that these poorly paid hospital workers don't pay taxes. **But the bad news is neither do the billionaires!** *No one* in Russia pays taxes!

The problems our Russian colleagues face are mind-boggling. And so is their dedication to the sick, and their determination to improve things, in spite of difficult working conditions and low wages.

So, what can be done to help these people? After years of war, fear and hostility toward their large neighbor, the Norwegian government decided it was time to move on and wiser to assist them. Audhild Hjalmarsen and her fellow physicians in Tromsö hold training programs for Russian physicians in Tromsö, and are also going to Russia to teach. The Norwegian government sponsored our Russian physicians for this visit to America. Audhild Hjalmarsen goes even beyond that, and is becoming the physician equivalent of Florence Nightingale in Russia. She personally has delivered 40 oxygen concentrators, plus IPPB machines and other used equipment to the hospitals in Karalia and St. Petersburg. This is not an easy task. When border guards check her van, she has to be careful that they don't confiscate some of her supplies to sell on the black market. That is how they supplement *their* meager salaries.

Vladimir Kozlov told us what it was like to live in a closed society, without access to the outside world for so many years. He has relatives who were able to get out of Russia many

years ago; they are now living somewhere in South America or perhaps in the States. Because contact was forbidden for so many years, they are lost to each other.

In 1985, when Dr. Jan Zielinski of Warsaw, Poland visited us, we were able to help him with donated, refurbished equipment because the Polish-American Societies did the shipping. Russia has been isolated from the rest of the world for so long that they are cut off from the old friends and relatives who escaped Communism. It is not ex-party members that we are trying to help. They, apparently, are doing quite well. What we learned was that the average Russian was trapped in the system, just as Eastern Europeans were.

If any person or organization is feeling a little philanthropic, and wants to donate used equipment, or an oximiter, we personally know 2 very dedicated physicians who would be most appreciative. However, since there is sometimes a problem with having donations "liberated" we will have to research the best way of delivering things so they get where you want them to go. Let us know if you are interested in having us work further on this problem.

While we have spent most of this newsletter on our guests from Russia and Norway, we don't want to neglect two other members of our panel at CSPR on rehabilitation in other countries . One was our very good friend and Webmaster, Dr. Janos Porszasz, who told us about pulmonary rehab and medicine in Hungary. We dedicated an issue to this after our return from Hungary last September so we won't repeat ourselves. However, we would like to tell you about the big laugh he got during his presentation. He showed a slide of Deszk hospital in Hungary, the luxurious ex-residence of a Count, surrounded by lush grounds, fountains, lakes, statues and, well…. you get the picture. He dryly announced, "This is where Dr. Attila Somfay has his rehabilitation program. I have come up in the world and this is where I am now Technical Director of the Rehabilitation Trials Center." The picture flashed on the screen to a view of our beloved but rather dingy Harbor-UCLA Research and Education Institute temporary building with the dirt parking lot next to it. It is definitely not someone's former palatial estate. The audience hooted in appreciative laughter.

Last but most certainly not least, **Dr. Hideki Tsurugaya** told us about pulmonary rehab and medicine in Japan, apologetically explaining that he is a cardiologist, just now learning about pulmonary rehab. That produced an appreciative round of applause and lots of good-natured comments about how unique it was to have a cardiologist interested in pulmonary rehab. Dr. Tsurugaya is at Harbor-UCLA for 2 years doing research on breathing, but is interested in visiting rehab programs, especially those that combine cardiac and pulmonary rehab. He hopes to start such a program in his hospital when he returns to Japan.

We were told that there are more than 5 million patients in Japan with COPD probably because of the problems with smoking as well as the aging of the

population. He felt they needed more rehab programs plus doctors, nurses and physiotherapists trained in this specialty. Japan also has problems with insurance coverage from the government. When HOT (Home oxygen therapy) was first covered in 1985, 100,000 patients signed up for it! He felt the same expansion would occur once rehab was covered. In Japan, he told us, many patients become house-bound or even bed-bound because it is so difficult to remain active. Of course, this same problem occurs in this country. The Japanese Respiratory Society recently published a pulmonary rehabilitation manual that physicians are beginning to use. In some of the large cities like Tokyo, pulmonary rehab is at the same level as it is in the United States. They also have an active patient support group and are part of an international effort to encourage recognition of the problems of COPD. Our cardiologist got a big round of applause for contributing to our meeting, plus several invitations to visit pulmonary rehab programs.

If you are on…….

our subscribe@perf2ndwind.org mailing list you already know the big news we have been waiting for. The good news is that on **June 5th Spiriva (Tiotropium Bromide) will at last come on the American market.** The bad news, as expected, is that it will not exactly be cheap; costing about $3.00 a day. However, one dose of Spiriva will probably eliminate multiple does of other inhalers you may be taking. This inhaler is useful *only* for those with COPD and apparently is not effective in asthma. Check with your physician to see if this medication is appropriate for you.

PERF would like to thank the following people for remembering us with their donations.

Dr. Richard Casaburi *donated the honorarium he received for his wonderful talk to CSPR.*

Another donation was made to the ***Jerry Donatoni memorial by Stella Donatoni and the L. A. County Dept. of Health Services, Maternal, Child and Adolescent Health Program.***

Jackie & Ken Rubinwitch *made a memorial donation for Dorothy Zahner.*

Alvin Grancell told us that he was able to get a **Nonin pulse oximeter** without a prescription for $325 from Med-Electronics, Inc. Telephone (301) 345-8826. In calling this number, we were told that the price was less if ordered through the Website, www.web-electronics.com. The price listed there was $287.77 plus shipping and tax if applicable. It is worth checking out for yourself if you are considering getting an oximeter.

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 the gracious permission of **Editor Kris Brust, RN, and Dr. Webb,** we share it with you.

HERB on HERBALS
PART 3 of 5 parts

"The world is flat. If some is good, more is better. Natural is safe."

Famous examples of misguided logic
by Herbert H. Webb, MD

Let me start by saying that I am definitely not an expert on herbals. My perspective is that of a skeptical, professional, conservative, mainstream pulmonary physician, and my watchwords are "Prove it to me that it is safe and effective before I put it into my body or recommend it for you."
I approach this task hoping to accommodate an attitude that herbals can be complimentary rather than an alternative to conventional medications.

We know both Western-type drugs and herbal medications exert chemical effects on the body, some therapeutic, some potentially dangerous. We also know that lots of people out there are medicating themselves with herbal remedies, probably more than will admit it to their doctors, lest they be given "that look". Most of my patients dislike taking medications, so given that both Eastern herbals and Western pharmaceuticals are indeed drugs, why are people so eager to take herbals and megavitamins?

In part one, I discussed a couple of ideas. First, the idea of dosing yourself with an easy to obtain and easy to take pill is appealing. We Americans have a strong urge for self-control and controlling our own destiny. No doctors, long waits in waiting rooms, pharmacies, etc. ---just straight to the health food store. Also, the emphasis on prevention in a pill is enticing, especially when the alternative takes effort, requires a diet, exercise or stress reduction. For others, "old is good" --- it was good enough for Grandma, so it's good enough for me!

I think it's fair to assume that patients who treat themselves with herbal medications are hoping to relieve a specific condition, lengthen their lives, and improve their quality of life. The eagerness to try new herbal drugs probably comes from the fallacy that "natural is safe". Of course, there isn't any more reason to think that natural is safe than that "synthetic is not safe", but it's funny how enticing that "natural" label can be.

THE BETA CAROTENE FIASCO
Here are a couple examples of applying misguided logic to medical issues. First comes the beta carotene fiasco of the late 1980's and early 1990's. A widely publicized study was based on surveys showing that people with high dietary intake of bioflavinoids (found in leafy greens, orange, red and yellow fruits and vegetables) lived better and longer, so the concept was that antioxidants protected us from cancer and heart disease. Great news! Beta carotene is a bioflavinoid. and so, the logic leap was made. Certainly taking a lot of beta carotene would be helpful. Well, the supplements industry just happened to have huge manufacturing capabilities for this one agent, and the medical profession went right along and widely recommended beta carotene.

In 1996, a large double-blind intervention study revealed *no effect on*

cardiac disease or malignancy. This was surprising, so a *second* placebo controlled study in Finnish smokers was undertaken, with even more disturbing results. The Finnish study showed beta carotene increased the incidence of lung cancer by 18%. *A third double-blind study in smokers re-confirmed the lung cancer increase, as well as increased cardiac death and increased mortality compared to placebo.*

The current unsurprising recommendation is that nobody should take supplementary beta carotene. What happened? Beta carotene is one of about 600 bioflavinoids in our diets. It was a crude oversimplification by the medical profession to assume that taking one of these bioflavinoids in large amounts would be as beneficial as a balanced healthy diet high in antioxidants.

IF A LITTLE BIT IS GOOD, A LOT IS BETTER. (*Wrong*.) Here's another misguided logic leap, the Vitamin A issue. Vitamin A is an essential vitamin found in highly pigmented vegetables. Vitamins A, D and E are fat soluble vitamins, so they can be stored in your tissues if taken in excess. Excesses of water soluble vitamins, like Vitamin C and B, are simply urinated out of the body. In any case, in underdeveloped countries, Vitamin A deficiency leads to blindness. On the other hand, *hypervitaminosis A* (too much Vitamin A), which is induced by more than 50,000 U per day for 3 months, causes mouth sores, dry scaly skin, hair loss, increased brain pressure, lethargy and death by liver toxicity.
Similarly, great excesses of fat-soluble Vitamin D can cause kidney failure and death. Even excessive iron intake is dangerous. Vitamin B6 in just slightly more than recommended amounts can cause peripheral sensory neuropathy --- this means that hands and feet become numb and don't function well.

Next month Dr. Webb will continue with Part 4. ***Positive Study Results on Herbal Drugs****, and* ***Separating Objective from Anecdotal Evidence.***

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We regret to inform you that Dr. Tom Petty, has again been hospitalized with a serious cardiac problem. He requests your prayers and good wishes, but no flowers please.

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Dear Friends:

DROWNING IN SALT (Part II)

A Brief History of Salt:

Salt is sodium plus chloride. The ocean has large supplies of salt as does certain lakes like the Great Salt Lake and the Dead Sea of Israel. The salt is concentrated through the evaporation of water and creation of "salten seas". Since salt creates buoyancy, it aids in floating and swimming. Thus salten seas becomes spas for some people.

Historically salt has been extremely important in the preservation of food. Salting meat and other animal products has been particularly important in preventing spoilage.

Salt mines at one time were more valuable than gold mines, because salt created the opportunity to process foods and allow for travel across continents and voyages over seas. Fishes and some vegetables were stored in "brine". Thus salt was of great importance to mankind, and allowed for exploration of our planet. During this period, the salty taste of preserved food became the "norm".

Salt is crucial to life itself and fundamental to good health. (See Part I – April 2004 Issue). But too much salt is present in most foods in the American diet. In both the Western and Oriental diets, salt can be devastating to good health. Salt promotes hypertension, stroke, fluid formation, and heart failure. Thus salt control is extremely important in the presence of cardiovascular and other diseases. Some diseases of the liver and kidneys also cause edema formation. Here again salt restriction and the judicious use of diuretic drugs is important in managing the internal environment of the body to maintain the balance known as "homeostasis".

The next installment will deal with dietary sources of salt and how to control your salt intake.

I'll be in touch next month.

Your friend,

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