

## The Scleroderma Foundation Applauds Introduction of First Bill in Congress Promoting Research and Awareness of Scleroderma

The Scleroderma Foundation hailed Rep. Lois Capps (D-CA) and Rep. Vern Ehlers (R-MI) for introducing H.R. 2408, the "Scleroderma Research and Awareness Act," in the House of Representatives. This bipartisan legislation gives hope to the estimated 300,000 Americans and their families living with the many terrible effects of Scleroderma.



Lois Capps

The "Scleroderma Research and Awareness Act" would:

Direct the National Institute of Arthritis and Musculoskeletal and Skin Diseases at the National Institutes of Health to expand research related to scleroderma. The legislation authorizes \$25 million in FY10, \$30 million in FY11, and \$35 million in FY12 for this purpose. Priority areas include:

Development and evaluation of new treatments.

Research on the relationship between scleroderma and secondary conditions including pulmonary hypertension, gastroparesis, Raynaud's phenomenon, and Sjögren's syndrome.

Establishment of family and "childhood-onset" patient registries.

Support for the training of new investigators.

Directing the Centers for Disease Control and Prevention to establish a scleroderma public awareness campaign highlighting disease symptoms, prevalence, related conditions, and the importance of early diagnosis. The legislation authorizes \$2.5 million in FY10, FY11, and FY12 for the awareness initiative.

LETTER REGARDING THE "SCLERODERMA RESEARCH AND AWARENESS ACT"

Dear Representative Elton Gallegly,

Thank you for your leadership in the House on health care issues. As a constituent, I am writing to encourage you to co-sponsor H.R. 2408, the "Scleroderma Research and Awareness Act." This bipartisan bill sponsored by Rep. Lois Capps (D-CA) and Rep. Vern Ehlers (R-MI) was introduced in the House on May 14th.

Scleroderma is a chronic and disabling connective tissue disease resulting from an overproduction of collagen. The word "scleroderma" means hardening of the skin which is one of the most visible manifestations of the disorder. Scleroderma can affect many areas of the body including the heart, lungs, kidneys and gastrointestinal system. There is no known cause and no cure. Women account for 80% of all diagnoses. The estimated total economic impact of scleroderma in the United States is \$1.5 billion annually. The direct cost of treatment for patients is more than \$460 million annually. Despite these burdensome figures, the federal investment in scleroderma research is only \$20 million a year.

As a man suffering with this disease and a former physician who has lost his career to this disabling disorder, I feel it important to lend my voice in urging you to support H.R. 2408. Every dollar directed towards researching Scleroderma goes to further understanding and curing this and all auto immune disorders and bringing relief to their sufferers, now numbered at 25 million patients in the U.S. and counting

H.R. 2408 would do the following:

- Direct the National Institute of Arthritis and Musculoskeletal and Skin Diseases to expand research related to scleroderma. Priority areas include:
- Development and evaluation of new treatments.
- Research on the relationship between scleroderma and secondary conditions including; pulmonary hypertension, gastroparesis, Raynaud's phenomenon and Sjorgen's syndrome.
- Establishment of family and "child-onset" patient registries.
- Support for the training of new investigators

The legislation authorizes \$25 million in FY10, \$30 million in FY11, and \$35 million in FY12 for these purposes. It directs the Centers for Disease Control and Prevention to establish a scleroderma public awareness campaign highlighting disease symptoms, prevalence, related conditions, and the importance of early diagnosis. The legislation authorizes \$2.5 million in FY10, FY11, and FY12 for the CDC awareness initiative.

Thank you in advance for your consideration of this request. This legislation is very important to patients and family members living with scleroderma. I would appreciate it if you would advise me of your actions regarding your co-sponsorship. I look forward to hearing from you soon.

Sincerely,

Robert Rich, DC  
6649 Maplegrove St.  
Oak Park, CA 91377  
818-469-5456

**Scleroderma Foundation**

Southern California Chapter

11704 Wilshire Boulevard, Suite 250

Los Angeles, CA 90025

Tel: 310.477.8225

Fax: 310.477.8774

[www.sclerodermasocal.org](http://www.sclerodermasocal.org)

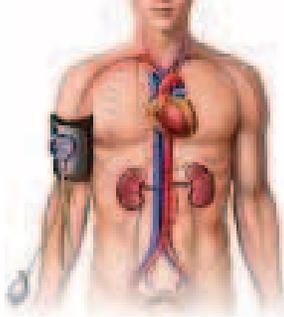
[sclerodermasocal@hotmail.com](mailto:sclerodermasocal@hotmail.com)

## BP For You And Me

Hypertension, or high blood pressure, is a serious complication of scleroderma that can lead to a variety of health problems such as heart attack, heart failure, stroke, and especially kidney failure, a devastating complication of systemic sclerosis.

Hypertension occurs when the pressure of blood against the walls of the arteries rises and stays high. Hypertension has been called the “silent killer” because it usually doesn’t have any warning signs. Many people don’t know they have it until their doctor tells them or a problem occurs. That’s why it is very important to check your blood pressure regularly both at home and at each doctor visit. You should do this even if you are feeling fine.

A normal blood pressure is less than 120/80. A BP of 140/90 or greater is considered unacceptable. While blood pressure can often be modified by weight control, moderate exercise, healthy eating, medications are often required in conditions such as scleroderma.



## Extra Help With Prescriptions

Social Security and the Centers for Medicare & Medicaid Services are working together to get you extra help with your prescription drug costs. If you have limited income and resources, you may be able to get help paying for your monthly premiums, annual deductibles and prescription co-payments under the Medicare prescription drug program that began January 1, 2006. To determine if you are eligible for this extra help, Social Security will need to know your income and the value of your savings, investments and real estate (other than your home).

Filing an Application for Help with Medicare Prescription Drug Plan Costs (Form SSA-1020) will help Social Security determine if you are eligible. Most of the questions on the application deal with income and resource limits. Social Security will not ask for documentation initially to support the information you provide, but will match your information with data available from other federal agencies.

## Health Quiz:

What was the biggest health care breakthrough in the last 40 years in the United States? Heart bypasses? CAT scans and M.R.I.’s? New cancer treatments?

No, it was the cigarette tax. Every 10 percent price increase on cigarettes reduced sales by about 3 percent over all, and 7 percent among teenagers, according to the 2005 book “Prescription for a Healthy Nation.” It is estimated that the 1983 increase in the federal tax on cigarettes saved 40,000 lives per year.

## Look Out Below!

Conquering the slopes and battling scleroderma was all in a day’s work as Mammoth Mountain played host to the skiers and supporters of Vertical Cure on Saturday, April 4th.

The premier scleroderma alpine downhill fundraising event once again challenged participants to schuss as many vertical feet as possible in a single day, with a goal to raise awareness of scleroderma as well as to secure charitable pledges in support of research into the disorder.

Organized by Chris Corman, an avid skier and outdoorsman, whose life was forever changed when his mother, Annette Crayton, was diagnosed with the disease, the Vertical Cure Scleroderma Foundation Ski Event is now in its seventh year, providing a day of friendly competition and fundraising.

To date, the frozen fun has raised up over \$150,000 while racing down magnificent Mammoth Mountain thousands of times. It is estimated that the participants have skied well over 6.4 million vertical feet for the cause, and have had nothing but the best of times doing it.

For further information about this and future events, Vertical Cure can be contacted at 5001 Via Sereno, Torrance, CA 90505.



## “Energy Drinks” Potentially Harmful to Patients With Cardiovascular Disease

Consumption of energy drinks increases blood pressure and should be avoided by people with vascular diseases that lead to hypertension, according to results of a recent study that were published in the *Annals of Pharmacotherapy*.

The beverages, marketed to enhance cognitive function and stamina, usually contain caffeine, taurine, sugars, vitamins, and other nutritional supplements, and pose potential hemodynamic and electrocardiographic changes that have not been properly studied.

To look into this, researchers studied 15 healthy volunteers who abstained from other dietary sources of caffeine, beginning 48 hours prior to establishing a baseline. Measured over several days, large, clinically significant increases in blood pressure and heart rate were observed in the study that could detrimentally impact persons with known cardiovascular disease.

Even the youngest individuals in the study showed marked evidence of vascular constriction and increased blood pressure, suggesting that individuals with undiagnosed, premature cardiovascular disease could be at risk when using these popular over the counter beverages.

The researchers caution clinicians that consumption of these drinks could, theoretically, be a frequently overlooked cause of altered medication effectiveness or even hospital admissions or emergency department visits.



The nearest way to glory is to strive to be what you wish to be thought to be. — Socrates

# New Systemic Sclerosis Classification Created

Ah, what a rare breed we are!

It turns out that one in five patients with clinical symptoms characteristic of systemic sclerosis does not fit into the popular classification scheme that divides the disease into the diffuse and limited cutaneous subtypes, explained Dr. Thomas Krieg, a dermatologist at the University of Cologne, Germany.

This major limitation of the conventional classification system now in use was among the key findings from the German Network for Systemic Scleroderma registry, which includes 2,007 systemic sclerosis patients at 41 centers.

The discovery that so many patients were excluded under the conventional limited and diffuse two-subtype scheme prompted a joint committee of German dermatologists and rheumatologists who oversee the registry to create a new, more inclusive classification system by adding three more systemic sclerosis disease subtypes: overlap syndrome, undifferentiated scleroderma, and sclerosis sine scleroderma, explained Dr. Krieg.

Overlap syndrome was defined as a disease featuring major symptoms of scleroderma simultaneously with those of other autoimmune diseases such as dermatomyositis, lupus erythematosus, or Sjögren's syndrome.

Sclerosis sine scleroderma consists of Raynaud's phenomenon, pulmonary arterial hypertension, and cardiac or gastrointestinal involvement in the absence of skin alterations.

Undifferentiated scleroderma was defined as Raynaud's phenomenon and at least one additional major feature of systemic sclerosis in patients not meeting the full American College of Rheumatology criteria. Such features include nail-fold capillary changes, pulmonary hypertension, puffy fingers, or having scleroderma-specific auto-antibodies.

Using the new extended classification, 48% of the 2,007 patients have the limited cutaneous systemic sclerosis subtype, 31% have the diffuse cutaneous subtype, 11% have overlap syndrome, 8% have undifferentiated scleroderma, and less than 2% have sclerosis sine scleroderma.

The uniquely large and inclusive scleroderma registry has had surprising findings. They include:

A family history of all types of rheumatic diseases was present in almost 20% of patients and was associated with a significantly younger age of scleroderma onset, along with a significantly earlier age at the onset of internal organ involvement. This suggests the importance of shared genes in a range of rheumatic diseases, according to Dr. Kreig.

The female-to-male patient ratio varied from 3:1 to 7:1, depending upon the systemic sclerosis subtype.

Skin manifestations typically preceded internal organ involvement in all of the disease subsets except sclerosis sine scleroderma.

The length of time between the onset of Raynaud's phenomenon and the beginning of skin and internal organ involvement was shortest for the diffuse cutaneous scleroderma subgroup and longest for the limited cutaneous variant.

Of all the patients, 60% had esophageal involvement and 50% had musculoskeletal involvement. Pulmonary fibrosis was present in more than 33% of the patients, oral jaw and gum involvement in 25%, involvement with the heart in 15%, the stomach in 15%, and the kidneys in 10%.

The specific organs involved varied according to disease subtype. Kidney, heart, and lung involvement were most common in the diffuse cutaneous subset. For example, the frequency of pulmonary fibrosis was 61% in the diffuse subgroup, compared with 31% in overlap syndrome and 24% in limited cutaneous systemic sclerosis. Musculoskeletal involvement was most common in overlap syndrome, with 69% of patients affected.

The systemic sclerosis registry is still ongoing. It is supported by the German Federal Ministry of Education and Research.

<b>Cutaneous</b>	<b>Renal</b>
Fibrosis of the skin	Renal crisis (hypertension, renal failure, microangiopathy)
Edema of the fingers and hands	
Digital ulcers and pitting	<b>Musculoskeletal/rheumatologic</b>
Calcinosis	Arthralgia, myalgias
Sclerodactyly	Median nerve entrapment
Telangiectasias	Muscle weakness
Flexion contractures and tendon friction rubs	
<b>Vascular</b>	<b>Gastrointestinal</b>
Raynaud's phenomenon	Gastroesophageal reflux
Nail-fold capillary changes	Peptic stricture
Digital ischemia and/or ulcers	Esophageal dysmotility
	Bleeding from ectatic vessels
	Bacterial overgrowth (with alternating constipation, diarrhea)
<b>Pulmonary</b>	Primary biliary cirrhosis
Alveolitis, interstitial fibrosis	
Pulmonary hypertension	<b>Endocrine</b>
Restrictive lung disease	Hypothyroidism
Aspiration pneumonitis	
Chest wall restriction	<b>Neurologic</b>
	Carpal tunnel syndrome
<b>Cardiac</b>	Peripheral neuropathy
Arrhythmias	Trigeminal neuralgia
Conduction disorders	
Pericarditis, pericardial effusion	
Heart failure	

Data extracted from: Chatterjee. *www.clevelandclinicmeded.com*. 2002<sup>1</sup>; Ostojic and Damjanov. *Clin Rheumatol*. 2006<sup>2</sup>; Lonzei et al. *Arthritis Rheum*. 2001.<sup>3</sup>

Patients should exhibit the major criterion shown and two of the three minor criteria:
<b>Major criterion</b>
Proximal sclerodermatous skin changes (ie, proximal to the metacarpophalangeal joints)
<b>Minor criteria</b>
Sclerodactyly
Digital pitting scars of the fingertips or loss of substance at the distal finger pad
Bibasilar pulmonary fibrosis
Data extracted from: Chatterjee. <i>www.clevelandclinicmeded.com</i> . 2002 <sup>1</sup> ; Hausteil. <i>Dermatol Online J</i> . 2002 <sup>2</sup> ; Subcommittee for Scleroderma Criteria. <i>Arthritis Rheum</i> . 1980. <sup>3</sup>

The secret to creativity is knowing how to hide your sources.  
– Albert Einstein

## Scleroderma 'In' Sight

An echocardiogram, or an "echo test," is a painless procedure for looking into the heart that every patient with scleroderma should have. By imaging and measuring heart functions in real time, important changes can be detected early and steps can be taken by Cardiologists and Rheumatologists to lessen their impact.



You don't have to stay in the hospital and it's not a surgery, nor does the test use X-radiation. The echocardiogram test instead uses ultrasound waves to show images of the movement of the heart and valves. These views can help determine its size and shape, any weaknesses or thickening in a wall or section, any valve problems and how well the heart is working overall.

Check with your doctor if you haven't recently been tested to see when this very important examination can be scheduled.

## Things To Remember For Better Living

1. Remember to take a 10-30 minute walk every day. And while you walk, smile. It is the ultimate anti-depressant.
2. Remember to sit in silence for at least 10 minutes each day. Buy a lock if need be.
3. Remember to tape your late night shows and get more sleep.
4. Remember to eat more foods that come from trees and plants and eat fewer foods that are manufactured in plants.
5. Remember to make peace with your past so it won't screw up the present.
6. Remember to clear clutter from your home, your car, and your desk.
7. Remember, however good or bad a situation is, it will change.
8. Remember to make least three people smile each day.
9. Remember to realize that life is a school and you are here to learn. Problems are simply part of the curriculum.
10. Remember not to take yourself too seriously. No one else does.
11. Remember that life isn't fair, but it's still good.
12. Remember that the best is yet to come. Enjoy the ride.

## Jumbled Thoughts

- If you're too open minded your brains may fall out.  
Don't worry about what others think, they don't do it very often.  
It isn't the jeans that make a butt look fat.  
Artificial intelligence is no match for natural stupidity.  
My idea of housework is to sweep the room with a glance.  
It is easier to get forgiveness than it is to get permission.  
Bills travel through the mail at twice the speed of checks.  
A conscience is what hurts when the other parts are feeling too good.  
Men are from Earth. Women are from Earth. We've got to deal with it.  
No man has ever been shot while doing the dishes.  
A balanced diet is a cookie in each hand.  
Middle age is when the broadness of the mind and the narrowness of the waist switch places.  
Junk is something you keep for years and throw away a week before you need it.

## Scratching Relieves Itch by Quieting Nerve Cells

As common as it is, scratching to relieve an itch has long been considered a biological mystery. Are cells on the surface of the skin somehow fatigued and in need of outside stimulation? Or is the impulse, and its relief, centered in the brain?

Perhaps neither one, a new study suggests. Neuroscientists at the University of Minnesota report that specialized cells in the spinal cord appear to be critically involved in producing the sensation of itch and the feeling of relief after the application of fingernails. The study appears in a recent issue of the journal *Nature Neuroscience*, and is the kind of work that should help open this area up to more research.



In the study, researchers isolated in monkeys the cellular/neurological connections that run from the surface of the foot to the spinal cord and then to the thalamus, a clearinghouse for sensations in the brain, then back down through the spinal cord to the surface of the foot. They then induced the sensation of itching by injecting histamines under the skin.

The scientists took single-cell recordings at the base of the spinal cord, in the lower back, in so-called spinothalamic neurons. These cells are sprinkled throughout the spinal cord. Most are sensitive to pain, and some to both pain and itch. The cells apparently detected the injection and began firing immediately afterward. And when the researchers scratched the itchy skin on the monkeys' feet, it quieted the cells' activity.

It was the first time that a noxious stimulus — the scratching — was observed to stop the firing of cells.

Some scientists believe that itching evolved to protect animals against some toxic plants, as well as insects, along with the diseases they can transmit. But the biology of the itch has been a mystery, and neglected for years by researchers, who have been far more focused on pain.

More than 50 diseases can leave people in a misery of itching. Studies among patients suffering many conditions have found that itch is among their top complaints. When it is severe it keeps people up at night, often worsening their condition.

The new study suggests that itch, like pain, may be a "gated" system in which signals from other nerve cells can interfere with or moderate the sensation. Scratching the skin near, but not directly on, the spot that itches often provides relief, just as rubbing an aching limb can reduce pain.

The researchers said it could be a while before doctors could expect new treatments to arise from this work. For one thing, the miserable, chronic itch common in many medical problems most likely involves other mechanisms in addition to those identified in the study, and activities in the brain may be critically involved in escalating an itch in ways that are not yet understood. But clinicians are expressing excitement about the findings as a sign that this field is really evolving and may provide new strategies for controlling this common and mostly unpleasant sensation.

Don't just believe in miracles - depend on them. — Laurence J. Peter

## FDA Warning

A growing number of US consumers, including some scleroderma patients experimenting with alternative treatments, are engaging in the potentially risky practice of purchasing medications from unregulated Websites that ship drugs from foreign countries. The Food and Drug Administration (FDA) has cautioned consumers about this practice, especially about ordering prescription drugs without a valid prescription. In addition, drugs that are available from overseas pharmacies should be monitored by a health professional for effectiveness and for potential adverse events, FDA officials have said.



There are several different types of Internet pharmacy portals, and some of them do follow safe medication practices. In the best-case scenario, a valid, legal prescription from a licensed prescriber is transmitted to the Internet pharmacy, which then fills the prescription and mails it to the patient. Pharmacies meeting quality standards of care are designated as Verified Internet Pharmacy Practice Sites (VIPPS) by the National Association of Boards of Pharmacy.

In contrast, legitimate prescriptions transmitted to pharmacies outside the United States may be filled with counterfeit drugs, expired drugs, illegally diverted drugs, or adulterated drugs. Even worse, consumers may order prescription medications online without first acquiring a legitimate prescription, giving them access to potentially toxic or addictive medications without seeing a healthcare provider.

There are many dangers to bypassing a licensed US prescriber and obtaining medications overseas. Perhaps the most troubling is the lack of a valid prescription, because the consumer may be self-treating with drugs not available for their condition in the U.S. Foreign medications may be addictive, be potentially toxic, or require special monitoring. There is often no assurance that the dosage is correct, nor is there screening for drug-drug or drug-disease interactions.

Other concerns about drugs obtained overseas include inadequate or inaccurate labeling, inappropriate packaging, and questionable storage and handling.

If patients are insistent about using Internet pharmacies, they should use only pharmacies that have received the VIPPS designation and require a legal prescription before dispensing any medication.

---

## More Medical Myths

One big myth is that fruit juice is a healthy part of our diet. Wrong. Drinking a glass of fruit juice a day — which is the equivalent of one soft drink of 110 to 180 calories — has been linked in the U.S., Australia and Spain to increased calorie intake and higher risks of diabetes and heart disease.

Eating a piece of fruit provides vitamins, fiber and, best of all, tends to reduce intake of other food. Most fruit juices are just sugary beverages, providing extra calories — all from refined carbohydrates — without satiating appetite. And this is true whether you drink apple or orange juice or one of the fancy new juices like acai berry or pomegranate juice. The added calories can contribute to weight gain and increased risk of both diabetes and heart disease.

People sometimes think that foods with the most vibrant colors are the ones that are most healthy for you. This is true to an extent. Dark green leafy vegetables contain high concentrations of Vitamin K and iron, yellow ones have lots of Vitamin A and beta carotene, while the purple fruits and vegetables tend to be packed with anti-oxidants.

Yet some of the duller-colored fruits and vegetables, commonly thought to be less beneficial, are also nutritional powerhouses. White cabbage happens to be one of the most nutritious foods you can eat, packed with Vitamins K, C, A, B and even calcium, iron and fiber. White beans? They've got as much protein and fiber as red or pink pinto beans. Even celery, with its watery make-up and greenish pallor has calcium and protein in addition to Vitamins A, C and K, and is pretty low in calories to boot. Perhaps the palest produce of them all, white cauliflower is a dense nugget of vitamin and antioxidant power.

The list goes on, but the point's clear (or off-white, pale green or beige)— don't judge the nutritional value of a plant by its color alone.

## New Study Shows Wide Benefit From Statins

We keep hearing of possible new usages for statins in scleroderma. The most recent evidence surfacing in closely related fields suggests that, in addition to their ability to lower cholesterol, medications such as Atorvastatin (Lipitor) may promote the reduction of inflammation in the body that plays a part in vascular damage.

A large new study suggests that millions more people, including those with scleroderma, could benefit from taking the cholesterol-lowering drugs known as statins, even if they have low cholesterol, because the drugs can significantly lower their risk of vascular damage, heart attacks, strokes and death.

Involving nearly 18,000 people worldwide, the research tested statin treatment in men 50 and older and in women 60 and older who did not have high cholesterol or histories of heart disease. What they did have was high levels of a protein called high-sensitivity C-reactive protein or CRP, which indicates inflammation in the body. The trial was one of the few to test the effectiveness of statins on women, Hispanics and blacks, groups that turned out to all show similar benefits.

The study, presented Sunday at an American Heart Association convention in New Orleans and published online in The New England Journal of Medicine found that the risk of heart attack was more than cut in half for people who took statins.

Those people were also almost 50 percent less likely to suffer a stroke or need angioplasty or bypass surgery, and they were 20 percent less likely to die.

Statin usage was considered so beneficial that an independent safety-monitoring board stopped what was supposed to be a five-year trial last March after less than two years, finding the statins to be very well tolerated, with the few risks of adverse reactions greatly outweighed by its effectiveness.

The study, called Jupiter, is also fueling a debate among scientists about CRP's importance and inflammation's role in all types of vascular diseases.

Current practice is to only treat people with high cholesterol with statins, but the Jupiter research suggests expanding statin use to patients with high levels of CRP could prevent about 250,000 heart attacks, strokes, vascular procedures and circulatory deaths over five years.



Opportunity is missed by most people because it is dressed in overalls and looks like work. — Thomas Edison

## *In Memory of...*

### **Anastasia (Stacy) Peterson**

After a long and courageous fight with the many effects of scleroderma, Anastasia Peterson has passed away.

Born in St Louis, MO in 1959 and raised in San Pedro, CA, Stacy married her middle school steady, Kevin, and together they raised two sons, helping to form a nucleus of family that included parents, brothers, children and extended family here in the Southland.

A member of the Riverside Support Group, Anastasia will always be remembered by her countless friends and family.

### **Roslyn (Rozz) Block**

Inspiring all who knew her with a quick wit and a wonderful sense of humor, Roslyn Block has left us after a long and successful life of service to her family and to others.

Born in 1915, Rozz grew up in San Francisco, CA, married, and moved south to Los Angeles, where she and her husband Sydney raised two daughters, Marilyn and Barbara.

Rozz became involved with scleroderma as a caregiver when Marilyn became ill with the disorder, and worked many long hours in support of her daughter and the Foundation by helping to secure items for our Gala and with advertising. In addition, she devoted herself to the United Hostesses Charities, where she served more than 50 years, achieving their highest honors.

Rozz will be dearly missed by all who knew her.

### **Hilda Sanchez**

Hilda Sanchez was a member and great supporter of the Whittier Support Group.

Born in Tijuana, MX and raised in Huntington Park, Ca, Hilda achieved her Associate of Arts Degree from East Los Angeles College and became a Teacher Assistant before having to stop her career because of the onset of scleroderma. After retiring, she was known as a loving and caring spirit in her neighborhood.

Hilda will be remembered by friends and family for her strength, love of family, and her courage in her long fight against scleroderma.

## **Tadalafil Reduces Raynaud's Episodes in Patients With Scleroderma**

October 27, 2008 (San Francisco, California) — In the first randomized controlled trial of its kind, the drug Tadalafil reduced the duration and frequency of secondary Raynaud's phenomenon episodes in patients with scleroderma. It also decreased the incidence of ischemic ulcers when used with other treatments, according to research presented here at the American College of Rheumatology 2008 Annual Scientific Meeting.

Tadalafil is a promising agent in the management of patients with secondary Raynaud's phenomenon, particularly patients who do not respond to conventional vasodilators.

Unfortunately, current therapy for secondary Raynaud's phenomenon is considered suboptimal as there are limited drugs to treat it. Although secondary Raynaud's phenomenon affects less than 1% of the population, it can be quite serious when it occurs, resulting in ischemia and ulcers, especially in those with scleroderma.

The research suggested that Tadalafil therapy might also provide a treatment to reverse the narrowing of blood vessels seen in the lungs and hearts of patients.

Out of the 25 patients studied, all were resistant to conventional vasodilators, and were experiencing more than 4 Raynaud's episodes per week. They were randomly assigned to receive either 20 mg of tadalafil or placebo every other day for 6 weeks.

The results indicated a significant decrease in the frequency and duration of Raynaud's episodes and a striking improvement in the incidence and healing of ulcers. Patients taking Tadalafil experienced fewer Raynaud's episodes and the episodes were also of shorter duration. One patient actually experienced a complete resolution of Raynaud's phenomenon.

All of the 24 fingertip ulcers present at the start of treatment healed during Tadalafil treatment, compared with 3 of 13 in the placebo group. Only 1 new fingertip ulcer was reported in the Tadalafil group, compared with 13 new ulcers in the placebo group.

There were no serious adverse events associated with Tadalafil.

Patient global assessment, physician global assessment, and the effect of Raynaud's phenomenon and fingertip ulcers on activities of daily living, as assessed by the Scleroderma Health Assessment Questionnaire, also improved significantly for patients taking Tadalafil.

"These are very exciting data, because the effects on Raynaud's were much more dramatic than those seen in previous studies," said Leslie J. Crofford, MD, chief of the division of rheumatology at the University of Kentucky, in Lexington, and president of the American College of Rheumatology Research and Education Foundation. "But it remains to be seen whether the data will hold up in parallel-group studies."

## **Dear ScleroSun:**

While I was taking Lisinopril to control high blood pressure and help prevent kidney troubles in Scleroderma, I developed a hacking cough. My Rheumatologist referred me to an ear, nose and throat specialist, who shrugged and said this comes with age. He gave me a course of antibiotics. Eventually, my wife mentioned my cough to the pharmacist, who pointed out that this is a common complaint with Lisinopril. Lisinopril is an ACE (Angiotensin Converting Enzyme) inhibitor, which serves to relax blood vessels, lower blood pressure and protect the delicate kidneys. Like other blood pressure drugs in this class (Accupril, Altace, Benazepril, Captopril, Enalapril, Ramipril and Quinapril), Lisinopril can cause a hacking cough that won't go away with cough medicine. Yet these drugs have saved countless patients with scleroderma from renal failure. As Dr. Furst is fond of saying in our education meetings, the medicines we take to help us can and do create problems themselves. It's a trade off that our specialists are fully aware of. That's why it's so important to continue to fund research to find better, less toxic, ways to treat patients with systemic sclerosis and to foster awareness of our condition among health professionals that may be unaware of our unique concerns.

I was recently told by my doctor that I had developed anemia. It turns out that I've been taking Nexium for GERD, a common symptom of scleroderma. It turns out that proton pump inhibitors and other acid-reducing drugs can hinder the absorption of iron and other nutrients. Now I regularly take iron supplements and am no longer anemic. Minerals like iron and calcium are absorbed best when there is acid in the stomach. Powerful acid-suppressing drugs like Nexium have saved thousands of scleroderma sufferers from the erosive effects of gastric reflux, but can interfere with the process of absorption and may hinder the uptake of nutrients such as vitamin B-12. Inadequate levels of this vitamin also can cause anemia.

Be so strong that nothing can disturb your peace of mind. — Christian Larson

## From the Editor...

Hi Everybody!

As some may know, Diane and I have been taking a sabbatical this last year, putting our California lives on hold to enjoy time in Annapolis, Maryland, watching our grandchildren grow and thrive in the nearby community of Crofton. While we will soon be packing it up and heading back home to resume our busy lives in the Los Angeles and Ventura County areas, our time here has been both meaningful and instructive and will long be remembered as one of the best years of our lives.

My daughter Amanda and her husband Barrett have recently purchased a home here, and while he works in Washington, DC as a contractor involved with national security, she has the advantage of being a stay at home mom, dividing her time between play groups, meet-ups and new experiences for Will and Jack, and making plans for their third child, due in December.

Of course, there is so much more to living in the East than family. Having Baltimore and Philadelphia so close is wonderful for sports and entertainment, and then there's Atlantic City just down the road! Believe me, we're taking as much advantage of our time here as we can.

Washington is the most amazing city of all, and in case you didn't notice, big things are taking place in health care. The change in administrations has ushered in an era of possibilities. While the arguments emanating from Capitol Hill over bailouts, budgets and bonuses dominate the news media and may make things seem dysfunctional, the people who work in this amazing city are hard at it, implementing ideas that just yesterday seemed impossible.

Take, for instance, the 10 billion extra dollars the new stimulus bill will provide to the National Institutes of Health. Research projects long starved for funds, including those that directly affect those of us who have scleroderma, will now move forward, hopefully to quickly advance new scientific breakthroughs into marketable approaches and fund promising new lines of investigation. The final bill at last took into account a desire for increased research dollars that has slowed medical progress at the NIH for years.

While the stimulus is a done deal, at least for now, the need for funding on other levels continues to exist. A new force for scleroderma on Capitol Hill is Congresswoman Lois Capps of San Luis Obispo, who has begun the steps necessary to introduce a bill in Congress to obtain additional dollars specifically for scleroderma research. After hearing the testimony of Southern California's Cynthia Cervantes, who traveled to Washington to increase awareness of Scleroderma and how it affects both adults and children, Congresswoman Capps volunteered to help lead the way in the fight against our medical nemesis.

These tantalizing tidbits are just a couple of recent developments that will have a direct, positive impact on those of us who suffer with scleroderma.

Diane and I have been thrilled to have been so close to the changing of the guard here in Washington and to see some of the remarkable developments taking place this year. Meanwhile, spring has sprung and summer will soon be here. Time for crabbing on the Chesapeake Bay!

California, here we come. Just not today.

All The Best,

Bob Rich and the Sclero Sun



*Sclero-Sun Editor Bob Rich*

## Walkathon 2009

If perfect weather, smiling faces, fabulous friends and family, great music, great food and a great walk in the park makes your day, what better place could there have been to experience all that and more than at the 7th Annual Southern California Chapter Scleroderma Walkathon in La Mirada Regional Park.

Thanks to the ongoing interest and efforts of Supervisor Don Knabe of the 4th District, the Los Angeles Department of Parks and Recreation, and all the wonderful teams, volunteers and exhibitors who made the much anticipated event possible, attendees had a great time enjoying the walk around the lake, through the trees and along the rolling pathways of La Mirada before settling down in shaded grassy areas to enjoy a delicious lunch provided by Baja Fresh and listen to the music of local band PCH, which provided aural inspiration for the day. In addition, as a very special thank you, VIP's who raised \$1,000 or more for their teams were acknowledged and treated to a relaxing massage and smoothie from Jamba Juice, who set up a promotional booth in the park.

Wherever you looked, children were giggling and screaming, occupied by the bounce house and mega slide, their laughter heard throughout the park, their faces adorned with butterflies and dragons, all thanks to the wonderful services of a talented face painter. The kids weren't the only happy young participants at the park. There were puppies and dogs as well, many wearing the colors of their teams, showing their support and companionship to their owners, as well as interacting with anyone willing to give them attention.

Once again, the annual Walkathon was a fun-filled, beautiful day, and a perfect way for people to show their support for the Southern California Chapter of the Scleroderma Foundation.



It is good to have an end to journey towards; but it is the journey that matters in the end. — Ursula K. Le Guin

# AARDA Implores Office of Research on Women's Health/NIH to Make Autoimmune Diseases Top Priority for the Next Decade

The American Autoimmune Related Diseases Association (AARDA) provided spoken testimony in support of autoimmune diseases being designated as a research priority for the Office of Research on Women's Health (ORWH)/National Institutes of Health (NIH). Written and spoken testimonies were accepted during the "Moving into the Future – New Dimensions and Strategies for Women's Health Research for the National Institutes of Health" which took place March 4-6, 2009 in St. Louis, Missouri. Through a series of scientific workshops, speeches, and testimonies the program aimed to explore new dimensions for the NIH women's health research agenda for the next decade.

AARDA President/Executive Director, Virginia T. Ladd provided compelling testimony, imploring the leadership of the ORWH and NIH to understand the extraordinary need to make autoimmune diseases a top priority for research. According to Ladd, autoimmune diseases affect more than 23.5 million Americans, with a disproportionate number of those affected being women at 75%. Autoimmune diseases are one of the top 10 leading causes of death among women 65 and younger. Ladd went on to say that the prevalence for many of these diseases are rising and very little is understood about the reasons why.

"Studies show that the incidence of multiple sclerosis in Italy has risen from less than 1 million cases in 1979 to over 4 million in 1999, in Norway and Sweden type one diabetes in children under 10 has risen from 8 million in 1930 to more than 20 million in 2000, in Finland type one diabetes has more than doubled in the last 30 years. Celiac disease in Minnesota tripled in the past ten years.

These studies show an alarming trend that we believe is occurring throughout the United States and the world. Researchers think that this increase is due to a combination of genetic predisposition and environmental factors. It is imperative that more research projects are developed to explore what in our environment is causing this increased prevalence. Additionally, there is a need to identify more biomarkers in women to determine predisposition to autoimmune diseases so that prevention might be a possibility." (An excerpt from Virginia Ladd's testimony, March 4th, 2009.)

Autoimmunity is a result of a misdirected immune system that causes one's own immune system to attack the self. There are over 80 known autoimmune diseases. Some of the over 80 autoimmune diseases are lupus, type I diabetes, scleroderma, celiac, multiple sclerosis, Crohn's disease, autoimmune hepatitis, rheumatoid arthritis, Graves' disease, myasthenia gravis, myositis, antiphospholipid syndrome (APS), and Sjögren's syndrome.

## Foods You Can Live With

Digestion, absorption and utilization. Those are the three most challenging aspects of any meal, especially when an intestinal tract affected by Scleroderma isn't up to the task.

Suggested below are a variety of foods amounting to a full evening meal that are easy to eat and absorb, are full of nutrients and have a direct benefit to health.

So let's set the table:

**Sweet Potatoes** Sweet potatoes are on the list because of their big boost of beta-carotene, a fat-soluble pigment found in many orange vegetables and fruits. It is a powerful antioxidant that protects our cells by destroying the free radicals that can damage cells (including skin cells) and cause age-related disorders. The body converts beta-carotene to vitamin A, which helps your skin, so incorporating sweet potatoes into your diet can help maintain it's structure. Beta-carotene also may protect skin from the damage caused by sun exposure. One cup of cubed sweet potato contains an amazing 14,000 micrograms of beta-carotene.

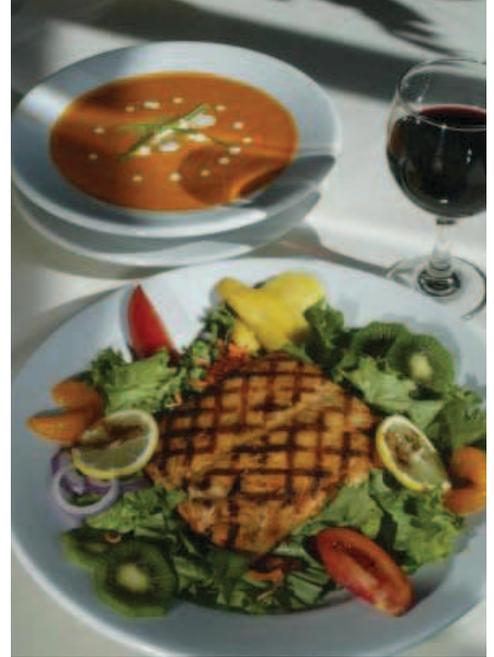
**Blueberries** Today the blueberry is experiencing a new level of popularity, not because it has a significant amount of any one vitamin or mineral but because, like sweet potatoes, it has an huge antioxidant profile. Researchers at a U.S. Department of Agriculture (USDA) laboratory at Tufts University in Boston, Massachusetts, rank blueberries number one in antioxidant activity when compared to 40 other common fresh fruits and vegetables. Blueberries contain many plant compounds that combine to make this sweet fruit an antioxidant superstar. Blueberries, because of their antioxidant, anti-aging, and anti-inflammatory effects, appear to be very helpful in wound healing.

**Tomatoes** Tomatoes make the list because they provide the greatest amount of the antioxidant lycopene, the bright red carotenoid pigment that gives tomatoes, watermelons, and pink grapefruit their distinctive color. Believe it or not, tomatoes are one food that is best enjoyed processed. The lycopene in tomatoes is actually more easily absorbed by the body after it is processed into juice, sauce, ketchup, or canned tomato puree. Ounce for ounce, the greatest source is canned tomato paste. It's a great staple to keep in your pantry to add to soups or stews for an antioxidant boost.

**Green Tea** Green tea is the only tea that contains a significant amount of the antioxidant epigallocatechin gallate (EGCG). Both green and black tea have about eight times the polyphenols found in fruits and vegetables, but green tea, unlike black and oolong tea, is not fermented, so the active ingredients remain unaltered. This wonder nutrient hunts for cell-damaging free radicals in the body and detoxifies them. The potential health benefits of EGCG include improved cardiovascular health and protection from the damage caused by ultraviolet light. Increased consumption of green tea has been shown to reduce the risk of skin, breast, lung, colon, esophageal, and bladder cancers.

**Wild Salmon** Salmon (especially the wild kind) is one of the healthiest foods you can eat. What's even more exciting is that consuming the pink fish can enhance the appearance on your skin. Salmon is one of the best food sources of omega-3 fatty acids, those beneficial fats that enhance our health and appearance by fighting inflammation, keeping our cells supple, improving circulation, and helping our brains function optimally. The omega-3s in salmon reduce help to reduce inflammation on the cellular level.

**Dark Chocolate** Chocolate may be described as sinfully delicious, but in fact it is a heavenly food with many virtues. Dark chocolate has made it to the table because it is a treat for your skin as well as your taste buds. Scientific articles published in the Journal of the American Medical Association and other journals reveal that dark chocolate contains as many polyphenols as red wine and has potent antioxidant properties. Chocolate contains many natural chemicals, including the beneficial flavonoids epicatechin and gallic acid, which are plant compounds that possess antioxidant properties.



## Banana Appeal

Bananas can be a part of a very healthy diet for those with scleroderma.

Containing three natural sugars—sucrose, fructose and glucose—combined with fiber, a banana gives an instant, sustained and substantial boost of energy. It is considered the number one fruit with the world's leading athletes.



But energy isn't the only way a banana can help us keep fit. It can also help improve a substantial number of illnesses and conditions, making it a must to add to our daily diet.

**Depression:** According to a recent survey undertaken by MIND amongst people suffering from depression, many felt much better after eating a banana. This is because bananas contain tryptophan, a type of protein that the body converts into serotonin, known to make you relax, improve your mood and generally make you feel happier.

**Anemia:** High in iron, bananas can stimulate the production of hemoglobin in the blood and can help in cases of anemia.

**Blood Pressure:** This unique tropical fruit is extremely high in potassium, yet low in salt, making it a perfect food to help with high blood pressure. So much so that the Food and Drug Administration allows the banana industry to make official claims for the fruit's ability to reduce the risk of blood pressure and stroke.

**Constipation:** High in fiber, including bananas in the diet can help with bowel actions.

**Heartburn:** Bananas have a natural antacid effect in the body.

**Mosquito bites:** Before reaching for the insect bite cream, try rubbing the affected area with the inside of a banana skin. Many people find it amazingly successful at reducing swelling and irritation.

**Nerves:** Bananas are high in B vitamins that help calm the nervous system.

**Ulcers:** The banana is used as the dietary food in many intestinal disorders because of its soft texture and smoothness. It is the only raw fruit that can be eaten without distress in most cases. It also neutralizes over-acidity and reduces irritation by coating the lining of the stomach.

**Stress:** Potassium is a vital mineral, which helps normalize the heartbeat, sends oxygen to the brain and regulates your body's water balance. When we are stressed, our metabolic rate rises, thereby reducing our potassium levels. These can be rebalanced with the help of a high-potassium banana.

A banana really is a natural remedy for many ills, and as a source for good nutrition, too. When you compare it to an apple, it has four times the protein, twice the carbohydrates, three times the phosphorus, five times the vitamin A and iron, and twice the other vitamins and minerals. It is also rich in potassium and is one of the best value foods around. So maybe its time to change that well-known phrase so that we say, "A banana a day keeps the doctor away!"

## Scientists Finally Find Out Why Bleach Kills Germs

Bleach has been used to kill germs for more than 200 years but scientists have just figured out how the cleaner does its dirty work.

It seems that hypochlorous acid, the active ingredient in bleach, attacks proteins in bacteria, causing the proteins to clump up and the bacteria to die, a team at the University of Michigan reported in a recent edition of the journal *Cell*.

The researchers had been studying a protein called heat shock protein 33, which becomes active when human cells are in distress from a high fever. They observed that as a person's temperature increased in response to infection, the human immune system naturally produced hypochlorous acid, apparently to assist in killing bacterial invaders.

They then found that as bacteria are exposed to bleach, heat shock protein 33 also became active in an almost identical manner, with proteins forming clumps that would eventually die off, demonstrating that bleach and high temperatures have very similar effects on proteins.

The discovery, which better explains how humans fight off infections and how healthy cells can become damaged during an illness, may eventually lead to new therapies in combating infectious diseases.

## Scleroderma Foundation

Southern California Chapter  
11704 Wilshire Blvd., Suite 250  
Los Angeles, CA 90025  
(877) 443-5755 -Toll free  
(310) 477-8225 -Office  
(310) 477-8774 -Fax  
(877) 443-5755 -Español  
email: sclerodermasocal@hotmail.com  
website: www.sclerodermasocal.org

We are a Chapter of the Scleroderma Foundation of Danvers, Mass. Dues are \$25 for an annual membership and should be mailed to the Los Angeles address.

**Executive Director:** Brian Ross Adams  
**President of the Board:** Daniel Furst, MD  
**Board Secretary:** Bonnie Davidson

## The ScleroSun

The Sclero-Sun is a publication of the Scleroderma Foundation/Southern California Chapter.

**Editor:** Robert Rich

Phone: (877) 443-5755 or (818) 991-7342

bobndi@sbcglobal.net

Article ideas are very welcome. Please call, email, or mail to:

ScleroSun, 6649 Maplegrove St.  
Oak Park, CA 91377

## Email Directory

The Chapter office maintains an email directory of all our members to facilitate important communications. If you haven't given us your email address, please send to: [sclerodermasocal@hotmail.com](mailto:sclerodermasocal@hotmail.com)

## Disclaimer

The Scleroderma Foundation and the Southern California Chapter do not endorse any drugs or treatments reported here. Information is provided to keep readers informed. Because the manifestations and severity of scleroderma vary among individuals, personalized medical management is essential. Therefore, it is strongly recommended that all drugs and treatments be discussed with the reader's physician(s).



Some have been thought brave because they were afraid to run away. — Thomas Fuller



# Scleroderma Foundation Southern California Chapter Calendar

## August-September 2009 Calendar

See Locations list for all addresses  
and contact information

### Visalia

Contact Lety

### Antelope Valley

Contact Carole

### August 08

Whittier/San Gabriel Valley  
10 AM to Noon

### August 09 (Sunday)

San Fernando Valley  
11 AM to 1:00 PM

### August 15

Crescenta Valley 10 AM to Noon

### August 29

Orange County 11 AM to 1:00 PM

### September 05

Ventura County 10 AM to Noon

### September 13 (Sunday)

San Fernando Valley  
11 AM to 1:00 PM

### September 26

South Bay 10 AM to Noon

## Standard Meeting Locations

### Antelope Valley

Contact Carole (661) 273-6952

### Crescenta Valley

Contact Joan (626) 824-0921  
jonettec@hotmail.com

### Orange County

Fountain Valley Hospital  
Saltzer Conference Room  
11170 Warner Ave.  
Fountain Valley 92708  
Contact Bonnie D. (714) 839-7034  
bjdsclero@aol.com

### San Fernando Valley

Sherman Oaks Hospital  
Doctors Conference Room  
4929 Van Nuys Blvd.  
Sherman Oaks 91403  
Contact Kelly (818) 974-2428  
Kelly@kellycryan.com

### South Bay

Oral and Maxillofacial Surgery Office  
1812 Artesia Blvd.  
Redondo Beach 90278  
Directions at  
<http://omsurgery.com/office1.html>  
Contact Valerie  
(310) 390-1717 (home)  
(310) 318-5970  
(weekdays except Weds.)  
DALEVAL@aol.com

### Spanish Speakers Club

Se Habla Español  
Chapter Office  
11704 Wilshire Blvd. Ste 250  
Los Angeles 90025  
Contact Josephine  
Oficina Esclerodermia  
(877) 443-5755

### Ventura County

Camarillo Health Care District  
3639 East Las Posas Rd. Ste 117  
Camarillo 93010  
Contact Arline (805) 987-8236  
TheWetters@msn.com  
Or Bob (818) 469-5456  
bobndi@sbcglobal.net

### Visalia

Contact Lety (559) 734-1011

### Westside

Chapter Office  
11704 Wilshire Blvd. Ste 250  
Los Angeles 90025  
Contact Josephine (310) 477-8225  
(877) 443-5755  
sclerodatasocal@hotmail.com

### Whittier/ San Gabriel Valley

Whittier Presbyterian  
Intercommunity Hospital  
12401 E. Washington Blvd.  
Whittier 90602  
Contact Norma (626) 369-2096  
normachew@roadrunner.com  
Myrna (562) 699-5080

## Additional Events:

### September 21 (Monday)

First Annual Golf Tournament  
Dove Canyon Country Club

### October 4 (Sunday)

Education Day  
UCLA DeNeve Plaza  
9 AM to 3PM

### November 7 (Saturday)

13<sup>th</sup> Annual Gala  
Manhattan Beach Marriott

Our attitude toward life determines life's attitude  
towards us. — Earl Nightingale