



Cold Cuts



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Scientists Come Closer to Demystifying Raynaud's

By Ronni Shulman
Vice Chairman, Raynaud's Association, Inc.

Researchers are coming closer to understanding the vastly complicated ways the human body regulates blood flow – knowledge that is key to treating, and stopping, Raynaud's phenomenon.

This was the message conveyed by world-renowned researcher Fredrick M. Wigley, M.D., as he addressed a joint forum of the Raynaud's Association and the Scleroderma Foundation's Tri-State Chapter in New York City during February. Wigley, Director of the Rheumatology Division at Johns Hopkins University in Baltimore, MD, was one of three presenters at the well-attended forum, moderated by Dr. Robert Spiera, Director of Rheumatology at New York's Beth Israel Medical Center.

Other presenters included Robert Reiner, Ph.D., Executive Director of Behavioral Associates, New York City, and James Weston, instructor at the Chinese WuShu Research Institute in Yonkers, NY.

Dr. Spiera reported that 30 percent of the population says they are more sensitive to the cold than other people. Three to 15 percent of individuals report the skin color changes that are associated with Raynaud's phenomenon.

"Primary" Raynaud's is not associated with any underlying problem, and is considered a benign condition. When Raynaud's occurs as a manifestation of another, more serious, disease such as scleroderma, lupus and



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Fredrick M. Wigley, M.D.
Director of the Rheumatology Division
Johns Hopkins University

rheumatoid arthritis, it is called "secondary" Raynaud's. An estimated 95 percent of people with systemic scleroderma, for example, suffer from Raynaud's phenomenon. In these instances, blood vessel damage also occurs along with skin color changes.

Cold temperatures and stress trigger the phenomenon, in which blood vessels constrict and fingertips turn from white, to blue, then to red.

Raynaud's is named for French physician Dr. Maurice Raynaud, who presented a paper around 1875 that described blood vessels not as rigid pipes, but as a sophisticated system that reacted to the environment. "Studies in the 1920's suggested that more women had Raynaud's because they were more uptight, a notion that was proved false," said Dr. Wigley, with a smile.

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Raynaud's Website Under Construction



Letter from the Editor
By Lynn Wunderman

After many starts and stops, we're happy to report our website is finally on course. For the past two years, I've been trying, unsuccessfully, to execute the site with the help of well-meaning volunteers and have finally come to the conclusion we need professional assistance.

For many of you, we are a 'long-distance' organization, with contact limited to mail or phone assistance and information. The web site offers an opportunity for outreach in the absence of active local chapters. A place to exchange ideas, questions, and knowledge that can benefit all of us — regardless of geographic boundaries.

Our goals for the site are:

- To provide easy, convenient access to information about Raynaud's and related health issues.
- To offer access to information about products and services that offer comfort and treatment for sufferers.
- To facilitate an open discussion forum for members.

We'll keep you posted on the expected launch date for the site and welcome all input and ideas you'd like to contribute. Please send them to: Lynn Wunderman, Raynaud's Association, Inc., 94 Mercer Avenue, Hartsdale, NY 10530 — or e-mail them to me at Lwunderman@aol.com.



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Biofeedback, Tai Chi May Ease Raynaud's

By learning simple relaxation techniques, some individuals can control the part of their nervous system that triggers Raynaud's attacks.

Raynaud's phenomenon is one of the disorders that may be alleviated by biofeedback, says Robert H. Reiner, Ph.D., executive director of Behavioral Associates in New York City. Appearing in February at a joint session of the Raynaud's Association and the Scleroderma Foundation's Tri-State Chapter, Dr. Reiner demonstrated state-of-the-art biofeedback technology and its ability to control muscle tension and skin temperature.

"When we get nervous, blood moves toward key body symptoms," Dr. Reiner explained. "This is known as the 'fight or flight' response, part of the autonomic central nervous system. Before the first biofeedback machines were introduced in the 1960's, it was believed that people couldn't control the autonomic response." Through training with a skilled biofeedback clinician, however, Dr. Reiner says

individuals can learn to relax their bodies. Consequently, Raynaud's attacks can be reduced, along with cardiac, gastrointestinal, muscular, neurological and anxiety-related disorders.

Dr. Reiner says biofeedback is a skill "like learning to ride a bicycle." To learn the technique, biofeedback sensors are attached to fingers, forehead or elsewhere on the body. As the person relaxes his or her body via imagery or breathing techniques, the machines "read" changes in body temperature, tension and other bodily processes, and then provide the user with visual or audio feedback. The biofeedback cues are tangible proof that the person is controlling the autonomic response.

"Practice is critical," Dr. Reiner stresses. Individuals must practice relaxation techniques on a daily basis before mastering the techniques. Eventually, they will be able to produce the same effect – controlling Raynaud's attacks –



without the need for the biofeedback apparatus.

Dr. Reiner agrees that biofeedback does not work for everyone. According to Raynaud's expert Dr. Fredrick Wigley, studies have shown that the technique has little benefit for most Raynaud's sufferers. But anecdotal reports indicate that others, primarily those people with primary Raynaud's phenomenon, do experience partial relief from the practice.

"Biofeedback is often an adjunct to medication, not a substitute," Dr. Reiner says. Finding a good clinician is very important, he adds. "He or she should have 5-10 years of experience doing biofeedback training. It's not necessary that the clinician be certified." The Biofeedback Society of America, however, is a good source for the names of local practitioners.

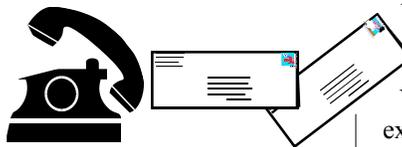
Other methods that are providing relief to some Raynaud's sufferers, including Raynaud's Association treasurer Kathy Laskowski, are Tai Chi and Chi Gong. Long used by the Chinese to provide energy and balance to the entire body, these techniques help the body to heal itself.

James Weston, an instructor at the Chinese WuShu Research Institute in Yonkers, N.Y., demonstrated a Tai Chi exercise at the February seminar. "These don't require the pretzel positions of yoga," he said. "Many senior citizens and those with disabilities can do it."

Tai Chi emphasizes long, fluid movements. The waist is turned and diaphragm is stretched while breathing becomes deeper and more relaxed. Weston acknowledges that Tai Chi and Chi Gong are not quick fixes. "They won't work for everyone, but they do reduce stress."

For more information about biofeedback, Tai Chi or Chi Gong, contact the Raynaud's Association.

Member Connections



This section is designed to help members identify others with similar needs and interests and to share information and coping tips.

Ginko Biloba and Vitamin E — Debbie Goodman Writes that she's had very positive results from both herbal remedies. Specifically, for Vitamin E she uses Thompson d-alpha tocopheryl acetate, which she highly recommends.

Editor's Note: While we're happy to hear members are experiencing success with herbal treatments, we also want to emphasize the importance of letting your physician know you're taking these remedies, as they can interact with other medications and can have serious side effects. For example, the Science section of the New York Times reported last year that Ginko can cause indigestion, headache and allergic skin reactions.

Anyone else wishing to connect with other Raynaud's members or share success stories, we're glad to publish them in our next issue: Cold Cuts, 94 Mercer Avenue, Hartsdale, NY 10530, or e-mail at Lwunderman@aol.com.

Hot Products for Cold Sufferers



We continue to review products that promise to make life easier and more comfortable for us "frosties". Not all products listed have been tested. Those which are still questionable are marked as such until we get more input from members.



Warm Cream

— Sounds too good to be true! A friend of mine gave me a jar of this cream as a gift, and I couldn't wait to try it. I've used it a few nights when I just couldn't get warm enough when going to bed (and my electric mattress pad hadn't hit full heat yet). Well, it seemed to help. Don't know how much was psychological and how much was real, but does it really matter? The product is found in the Self Care catalog. The copy says it's been laboratory tested to "restore circulation and normal body temperature to cold fingers and toes...works via transdermal absorption of the amino acid L-Arginine, relaxing blood vessels for up to 4 hours." To order, call 1-800-345-3371, or visit the web site at www.SelfCare.com.



Hotfingers Gloves

— A participant in the Scleroderma chat room on AOL wrote to rave about gloves she saw demonstrated on QVC. The host of the program put on the gloves, then stuck his hands in a tank of ice water. A temperature gauge in the tank registered his hands as normal temperature and dry. The product is called Hotfingers Comfortemp waterproof gloves, item # F16563. They sell for \$38.00 + sales tax, and shipping. The number at QVC is 800-345-1515.



Snowblocker Socks

— I found this product advertised in the Skymall catalog when I was on a business trip. I completely forgot about them all winter until I was writing this

column — rats! I would have loved to have tried them during the bad weather this year. These combo wool/cotton/nylon socks have a double cuff to ensure snow can't get in. Also keeps your ankles extra toasty. With these socks, I might actually be able to wear real shoes (as opposed to boots) on a cold winter day. Come in two sizes: M fits men's sizes 10-13; W fits women's sizes 9-11. Call the catalog at 1-800-SKYMALL, or go to the web site at www.skymall.com. Order item #12-149M/WA. Price is \$9.00 per pair.

If you've had good or bad luck with products promising warmth and comfort, please share your findings with us for future issues. Write or e-mail me at Lwunderman@aol.com.



Warmest Winter on Record!!!

The New York Times reports the Winter of 1999-2000 has set a record for winter warmth, with average temperatures of 38.4 degrees (still sounds cold to me!). This is the third straight year of warm winter records. Let's hope the trend continues!

Demystifying Raynaud's



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Raynaud's is most prevalent in young women, with the onset usually following the age of sexual maturity.

Color changes in Raynaud's sufferers are due to vasospasm (spasm of the tiny blood vessels in the extremities), induced by cold or emotional stress. Generally, Raynaud's attacks occur in three phases: a white blanching or pallor stage when skin loses its normal ruddy appearance; blue "cyanosis" stage where there's a pooling of blood that has lost oxygen; and a red "hyperemic" phase, when blood rushes back to the area.

The most serious phase is when fingers turn white, Dr. Wigley said. "This is when tissue damage is most likely to occur. When normal individuals experience cold temperatures, skin temperature and blood flow return to normal rather quickly when their fingers are re-warmed," he explained. "For Raynaud's sufferers, however, there's a prolonged and delayed recovery.

"The reasons why this occurs is a major subject of studies," he added. One theory is that people's bodies may simply vary, just as some people have large noses and others have small ones. The regulation of blood vessels is very complicated, with various backup systems in place to maintain blood flow. An imbalance in any of the systems can cause the constriction seen in Raynaud's patients.

Researchers are looking for clues in the body's thermoregulatory vessels, which help regulate body temperature and conserve body heat. A person's skin normally blushes and sweats to avoid overheating when it's hot, and the vessels constrict to conserve blood and body temperatures in central parts of the body when it's cold.

Some studies suggest that patients with Raynaud's have a defect in vasodilating hormones that are released from sensory nerves, Wigley reported. Another theory is that some Raynaud's sufferers — particularly those with scleroderma — have a deficiency of nitric

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Demystifying Raynaud's

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oxide, a chemical inside the wall of blood vessels that cause them to dilate.

The study of Raynaud's phenomenon in scleroderma patients, in particular, may unravel not only the mysteries of Raynaud's, but may also yield clues that will help researchers stop the progression of the whole disease. Skin biopsies of many scleroderma patients show a defect in sensory nerves. This abnormality is seen before other vascular disease in the body occurs. "In theory, then," said Dr. Wigley, "if we can control the abnormal sensory response, we may be able to impact the whole disease."

Relief for primary Raynaud's phenomenon is far simpler. The objective is to reduce vasospasms. Some medications – primarily calcium channel blockers – often help, Dr. Wigley said. Other drugs such as beta-blockers, narcotics, and those with caffeine may aggravate the problem. Of course, dressing warmly and avoiding the cold is still the first step.

Relieving secondary Raynaud's phenomenon requires easing

vasospasms plus avoiding blood vessel blockage, which causes ulcers and fibrosis of the extremities.

"Every medication that affects blood flow has been tried for Raynaud's," Wigley said. "Unfortunately, the effectiveness of even the best drugs is limited because none of them are directed only to blood vessels that control temperature in the skin." Calcium channel blockers (e.g., Norvasc, Procardia), which cause muscles to relax, are still the best bet, said Wigley. Other treatments under study include vasodilators; selective serotonin re-uptake inhibitors (e.g., Prozac); Viagra; and oral and intravenous prostaglandins (e.g., iloprost).

While various studies are underway, there are steps that Raynaud's sufferers can take now to avoid or decrease the severity of attacks. Some doctors suggest that antioxidants such as vitamin E and zinc glucomate (50 mg. daily) may reduce the frequency and severity of attacks. Baby aspirin on a daily basis may also help.



In a crisis, where severe ulcerations may lead to permanent tissue damage or amputation, anti-coagulation drugs (blood thinners) may help. Lidocaine may be injected into the hand (digital block), or microvascular sympathectomy surgery may be used. Relief is often temporary, however, Dr. Wigley pointed out.

To order a videotape of Dr. Wigley's complete presentation, contact Starlight Productions at 914/986-9112, www.starlight-productions.com.

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