



media contact: Lawrence Maushard
503-238-6605, maushard@gmail.com

“I wish I could be one of those snowbirds.” People living with scleroderma dreading the cold temps Specialist says it's "not enough to warm the hands and feet."

(Portland, OR., November 26, 2009) -- As if unhealed finger ulcers and restricted mobility aren't enough to deal with on a regular basis, try multiplying that exponentially during the cold and rainy season.

“If it is raining and colder, I can't go out; just warming up the car triggers the Raynaud's so badly my hands become numb,” Connie Osbon of Beaverton said. She lives with the autoimmune disease scleroderma and its related malady Raynaud's Phenomenon.

“The finger ulcers are especially getting bad to cope with since my hands are exposed to so many more irritants like hot water, soaps and the cold. Already I have them starting up again, and I never healed from last year, which was the worse one so far.”

Scleroderma [pronounced sclare-a-derma], or systemic sclerosis, is a chronic connective tissue disease generally classified as one of the autoimmune rheumatic diseases. The word “scleroderma” comes from two Greek words: “sclero” meaning hard, and “derma” meaning skin.

There are an estimated 300,000 people who have scleroderma, of which 80,000 to 100,000 people in the United States have the systemic form of the disease. If those with Raynaud's Phenomenon and one symptom of scleroderma were counted, the figure would be closer to 150,000. Also, there are many more people with the localized form of the disease.

“Raynaud's is almost universal in scleroderma patients. It's vasospasm (when [blood vessels](#) spasm, leading to [vasoconstriction](#)) of the arteries in the hands as a reaction to the cold and/or stress. It's a rare patient that doesn't have it,” according to Dr. Lauren H. Kim MD, a rheumatologist at the Legacy Clinic Northeast in Portland who trained at the Scleroderma Center at Boston University School of

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Medicine for her rheumatology degree, and at Yale Medical Center for her Internal Medicine training.

One of the very few scleroderma specialists in Oregon, Dr. Kim started a dedicated scleroderma clinic several years ago at the OHSU Division of Arthritis and Rheumatic Diseases, the only clinic of its kind in the state.

“The degree of discomfort and damage from Raynaud's varies quite a bit from person to person though,” Dr. Kim explained. “Some aren't bothered by it much and practically don't notice it. For others, it can be very painful and disabling. Some of the variation probably depends on pain tolerability by each individual but the other variable is the degree of vasospasm.

“For about 10-20% of patients with scleroderma, it can be very severe and for a much smaller percentage, 1% or less, they can develop digital ulcers that are ischemic (restriction in blood supply) in origin. The ischemia can lead to digital loss.”

For Osbon, the winter weather has been an unwelcome season for a long time. “I have been dealing with this since childhood with numerous light frostbite incidences while growing up in Alaska,” she recalled. “But the Oregon dampness and chronic overcast here really bothers me more. It is getting worse. I really dread winter approaching.”

Donna Stone, longtime head of the Portland-based Scleroderma Support Group, said that in general people living with the disease “begin noticing scleroderma responses as the temperatures begin to decline. The extremities begin reacting to the cold in the form of Raynaud's, such as blanching of hands, feet, nose, ears, and tongue.”

Scleroderma affects four times as many women as men, usually between the ages 46 to 65.

“Color changes in their hands to white, blue, and pink. And they begin feeling cold in general, sometimes with swelling, sometimes in pain,” Stone, who lives with the disease, added.

The support group is affiliated with the Oregon Chapter of the Scleroderma Foundation, a nationwide nonprofit organization formed in 1998 by a merger of previously existing advocacy groups based on the West and East coasts. The Scleroderma Support Group in Portland actually predates the national foundation by several decades having started in the late 1970's by a number of local women with the disease.

So what about simply bundling up as a way for people with scleroderma to deal with the cold?

“Dressing warmly and keeping the core body temperature elevated is a very good, inexpensive and a non-pharmacologic way to keep hands and feet warm,” Dr. Kim noted with a caveat. “But it's not enough to warm the hands and feet, because if the core body is cold, it will always divert blood away from the extremities to perfuse the heart and brain. If these areas are warm, (only then is) blood sent down the extremities.”

Specific drugs and treatments exist that can help scleroderma patients deal with the winter weather, Dr. Kim noted: “There are multiple medications that can be used to dilate the blood vessels and try to prevent vascular spasm. Calcium channel blockers (CCB) such as diltiazem and nifedipine are the

mainstays of therapy because they've been proven to dilate vessels and also to prevent spasm. There are several other proven therapies that I discuss with patients if CCBs are insufficient to control symptoms. I will either switch if they can't tolerate CCB or add another agent if CCB alone is insufficient to control symptoms.”

Scleroderma tends to affect everyone who has it in different ways, so it's often misdiagnosed and even undiagnosed at first. Its manifestations can range from extremely sensitivity to heat and cold to diminished lung capacity to disfigured face and limbs. Scleroderma can be fatal, and there is no known cure yet.

And the disease can cause additional burdens.

“The approaching winter makes me sadder because of the reduced activity level when I'm already limited in daily functions,” Osbon added. “Plus, it is a chore to stay warm, at least 70 degrees in my residence, and that costs me double in electricity rates.

“For several years I even attempted to work on creating a state statute to provide medically disabled persons with Raynaud's, heart disease, and other similar conditions obtain reduced utility rates, as is the case in California. Unfortunately, my good days were not enough to complete this endeavor.”

For now, Osbon can only hope for a mild winter. “I wish I could be one of those snowbirds you hear about.”

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For more information, visit www.scleroderma.org/chapter/oregon/ or contact the Scleroderma Foundation Chapter at 503-245-4588, SDForegon@comcast.net, PO Box 19296, Portland, OR 97280.

The Scleroderma Foundation is a 501(c)(3) national nonprofit organization serving the interests of persons living with scleroderma. The Foundation's 24 chapters and 147 support groups nationwide help to carry out its three-fold mission of support, education, and research. The Scleroderma Foundation is the leading nonprofit supporter of scleroderma research—funding over \$1M of new grants each year to find the cause and cure of scleroderma.