

# *Oregon Angels*

## **Staying Warm! Portland Support Group meeting hosts Dr. Lauren H. Kim with advice to best handle the winter season**

For most people living with scleroderma, the colder temperatures in the fall, winter and early spring tend to bring out the worst symptoms and the most trying times.

“The cold temps are uncomfortable at best and devastating at worst to those with Raynaud’s Phenomenon,” Dr. Lauren H. Kim MD said at the November 14 Portland Support Group meeting at Legacy Good Samaritan Hospital. “You can lose digits.”

It’s a rare scleroderma patient that doesn’t have Raynaud’s, according to Dr. Kim, a rheumatologist at the Legacy Clinic Northeast in



**A warm tropical setting was the perfect visual aid when Dr. Lauren H. Kim MD (right) was the featured speaker during November’s Support Group in Portland.**

Portland who trained at the Scleroderma Center at Boston University School of Medicine for her rheu-

matology degree, and at Yale Medical Center for her  
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## **Oregon chapter continues outreach at Portland Women’s Show**



**Chapter Treasurer Janine Wong (left) volunteered awareness and information at the Portland Women’s Show.**

Chapter volunteers staffed an informational booth during the three-day Portland Women’s Show October 30—November 1 at the Oregon Convention Center. Based on this year’s results, it looks like they’ll be back for a fifth straight event in 2010.

“Six people came up to us and said, ‘I think I have this,’ ” booth organizer and

Chapter Outreach Advocate Denise Bates announced at the recent Support Group meeting. “One woman was in tears, and said her dermatologist told her ‘there was nothing we can do.’ ”

Attendance at the weekend Show appeared to be down compared to past years,

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## Dr. Lauren H. Kim offers timely warming tips at the Portland Support Group

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 facility of its kind in the state.

“Layer, layer, layer is the best non-pharmacological way to deal with the cold,” Dr. Kim emphasized. “But it’s imperative to keep the core body temps elevated. The heart and head must be warmed first.” She explained that it’s not enough to warm

the hands and feet, because if the body core remains 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.”

In addition to warming the body core, Dr. Kim pointed out that it’s important to avoid rapidly changing temperatures, such as going from warm surroundings to air-conditioned environments; to minimize emotional stress; use hand warmers; and avoid smoking, which causes vasoconstriction.

“You can keep your hands warm with layers,” Dr. Kim added. “First with thin cotton gloves covered by a thicker glove and/or mittens.”

In more severe cases, the pharmacological means to treat Raynaud’s include Calcium Channel Blockers (CCBs). “CCBs such as Nifedipine, amlodipine, diltiazem, felodipine, nisoldipine and isradipine have been shown to be effective for Raynaud’s Phenomenon (RP),” Dr. Kim noted. CCBs also help reduce vasospasms (when blood

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## Oregon chapter continues important outreach at Portland Women’s Show

chapter officials noted. Still, the reasons for being there remained the same as always.

“People I came across said they knew others who had scleroderma,”

volunteer Cassie Manning remarked.

“If we can be in contact with



A section of the chapter’s colorful awareness booth displayed throughout the 17th Annual Portland Women’s Show at the Oregon Convention Center October 30-November 1, 2009.

anyone” as a result of the chapter’s presence at the show, then “it’s worth it,” added Support Group Leader Donna Stone.

The booth included the most up-to-date scleroderma information, as well as some great photos from past chapter events, like the recent *Stepping Out for Scleroderma* benefit.

“We gave out at least 100 walk brochures at the Show,” Bates remarked.

Not to mention lots of Halloween candy. “That always gets people stopping by.” []

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## Portland Support Group meeting deals with cold weather and more

vessels spasm, leading to vasoconstriction), she said.

Other medications include sildenafil or viagra, which improves pulmonary and peripheral circulation, Dr. Kim said. "It does seem to work. I've had people who had horrible RP, and it worked with them. But I don't use it very often because of cost, and because it has not been proven effective in a controlled trial."

Additionally, prozac (seemed to have an effect on blood pressure) and bosantan (helped prevent new ulcers) are also said to have benefits for RP patients.

In the most extreme situations, other methods are necessary. Dr. Kim remarked that "Some RP patients need to be hospitalized for severe limb and digit threatening ischemia (restriction in blood supply)."

### More areas of discussion

The Support Group presentation by Dr. Kim included a variety of discussion topics, including her updates from the annual meeting this October of the American College of Rheumatologists held in Philadelphia.

\* Dr. Kim said she belongs to the ACR's Scleroderma Consortium: "It started out in a small room at the annual meetings. Now it's a standing room-only session, but not near the size of the Lupus research find-

ings. Still, it's an exciting time."



### Dr. Lauren H. Kim:

*"Even a lot of rheumatologists have a negative view towards scleroderma. They say 'we can't do much for you.' Obviously, that's not true."*

\* Imatinib (Gleevec) is an anti-cancer drug partially developed at Oregon Health and Science University. In terms of scleroderma, which has several pathways that lead to thickening of the skin, Imatinib blocks those pathways. One trial sounded promising, and other people believed another trial was dropped prematurely. "Hopefully we'll have a large double-blind trial so we'll know once and for all."

\* Mycophenolate Mofetil "has been in the press a lot. It's just as good as cytoxane for lupus and arthritis, and used a lot by transplant patients. In an open label study of MMF for treatment of early diffuse systemic sclerosis, they observed

improvement in skin score and halted the progression of lung disease, but this needs to be confirmed in a controlled, blinded trial."

\* Up to 30 percent of people living with scleroderma have incontinence of the stool. A study was held to elucidate the mechanisms for anorectal sphincter muscle function in systemic sclerosis. It may help find the best ways of treating patients with the condition. Both structural and neurogenic mechanisms are likely to influence development.

\* St. John's Wort in a double-blind study was not effective for scleroderma. "The bottom line was it did not help, and is not recommended. It's helpful to have this data from a rigorous trial. Now we know."

\* Vascana is a novel topical nitroglycerine that causes less headaches. The topical applications may be good for some patients. "It seems to work to dilate vessels. I look forward to it being available."

### Q & A's

\* "Do you think scleroderma people are more susceptible to the H1N1 virus?"

"I think people with scleroderma are more at risk at getting infections in general. I tell all my patients to get their flu shots."

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## Central Oregon Support Group welcomes new member

by Ann Havelock

The Central Oregon Scleroderma meeting was held on Thursday, November 12 at Bend Memorial Clinic from 5:30 to 7:00pm.

In attendance were six people living with scleroderma and Trish Dyer, a certified hand therapist and the group coordinator. Trish discussed skin care, after which we all welcomed a new member who has lived with scleroderma for 30 years.

She had never talked to or met another person with the disease until our meeting and was excited to attend. She recently had been diagnosed with pulmonary hy-



The Central Oregon Support Group meeting in Bend drew a half-dozen people, including a new member.

pertension and is on oxygen twenty-four/seven. She works and really has a *true grit* attitude like the rest of us living with scleroderma.

A lot of questions were asked and stories shared by the entire group, making it hard to end the meeting and head for home.

**SUPPORT  
EDUCATION  
RESEARCH**

P.O. Box 19296  
Portland, Oregon  
97280-0296  
(503) 245-4588

orchapter@scleroderma.org

www.scleroderma.org/  
chapter/oregon

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## Dr. Lauren H. Kim featured at Portland Support Group meeting



Portland's Support Group meeting in November at Legacy Good Samaritan had 15 people.

\* "Are younger people getting more cases of scleroderma now, or is it simply better diagnostics and recognition?"

"I see scleroderma in all ages, but it's more common in women in their 40s and 50s. In younger people, I do see more instances of morphea."

\* "What are the first symptoms of scleroderma?"

"At the ACR meeting, there was a lot of controversy over what's considered the first symptom that's not RP. Something so basic you'd think should have been worked out decades ago, but we're still working on it." Puffy hands are a good first indicator but many doctors see that as rheu-

matoid arthritis, she said.

\* "What about a blood test?"

"That is good for patients to show if they have scleroderma. They need a blood test.

"And it's hard for primary care doctors to know about scleroderma. Even a lot of rheumatologists have a negative view towards scleroderma. They say 'we can't do much for you.' Obviously, that's not true.

"Unfortunately, it's not an exact science with the differences between limited and diffuse patients. But in a majority of scleroderma patients there is a pattern to detect."