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media contact: Lawrence Maushard  
503-238-6605, [maushard@gmail.com](mailto:maushard@gmail.com)

## **Scleroderma support group begins its fourth decade of service to Oregon and SW Washington**

### **Portland-based patient operated nonprofit organization providing a vital “connection with others” since 1981**

(Portland, OR., February 15, 2010) -- The lively crowd of about a dozen people met for more than two hours recently at Legacy Good Samaritan Hospital to discuss their personal issues and concerns about living with scleroderma.

Many there had attended the regular support group meetings for months and years. But what they may not have realized is the first meeting of 2010 in fact marked the group’s fourth decade of service to Oregon and SW Washington.

This incredible longevity, stretching back to 1981, if nothing else demonstrates the ongoing local demand for information, services and support among those living with this autoimmune disease.

“The group gave me a feeling of belonging, as I had never heard of the disease nor knew anyone who had experienced it,” Portland Support Group Leader Donna Stone (shown in pink) said about her first encounter with the group back in its inaugural year. “I felt that I had received help simply by hearing and sharing information from others. They gave me a sense of ownership and belonging. I was not alone.”



Someone who discovered the Portland group only a few months ago echoed those same feelings.

“Every person I met at Portland and here in Central Oregon seem to have that special ‘true grit.’ I am inspired by their attitudes,” Ann Havelock, a Bend hairstylist, commented. “I quit being a victim and am now a person living with scleroderma.”

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Ann took a passion for independence and helping others to the next stage by actually starting her own scleroderma support session. Her Central Oregon Support Group has met monthly in Bend since last summer.

“I decided to start a group here in Bend to bring people together in a safe positive environment,” Havelock noted, “to share our stories and not feel we are alone.”

That need to connect with others helped Stone find the Portland support group back before cell phones, email and WiFi.

“I was diagnosed by accident, having been to doctors for four years and wondering what was wrong. I went to a dermatologist for a chin rash and he suspected scleroderma and referred me to Oregon Health & Science University, where they suggested it might be scleroderma.

“Then my mother read a small blurb in *The Oregonian* newspaper, telling of a support group in Portland,” recalled the Ridgefield, Washington resident.

“We didn’t have a proper name, but we subscribed to a newsletter published by a lady, Arkie Barlet, with Scleroderma International Foundation, out of New Castle, Pa. She came out on several occasions to address our group. There were about nine of us at the time.

“Dr. Stanley Jacob and Loretta Roberts were the original organizers and a nurse also helped, though I cannot recall her name. But Loretta Roberts was the first support group leader.”



Asked to point out some of the biggest changes in the group over the decades, Stone replied, “Not a lot of changes. Mostly the same questions and concerns: *‘What is this dreadful disease? How is it treated? How will I be affected? Is there a cause, cure? What meds or procedures are used?’*”

“Today, however, there appear to be larger numbers of patients being located in area. And there is a desire to find more through awareness.

The support group joined the national Scleroderma Foundation as its Oregon Chapter affiliate about a decade ago in what’s turned into a beneficial partnership, said Stone: “Our current association with the Scleroderma Foundation has enabled us to be more proactive in our cause by providing information and support as part of a national organization.”

Since its start, the Portland Support Group has met at Legacy Good Samaritan Hospital. Meetings are held on the second Saturday at 10am every other month, unless there’s a special event (March’s Cheri Woo Education Seminar) or fundraiser (May’s Plant Sale and July’s *Stepping Out to Cure Scleroderma* benefit walk).”

Most of the strongest local advocates for scleroderma patients began by finding the support group.

“My doctor at the time gave me a brochure or paper that had Donna's phone number,” Maria Rivelli of Portland recalled.

This simple referral turned into a deep involvement with the support group, and Rivelli eventually became a member of its board of directors. One of her big projects is the group's annual *Stepping Out to Cure Scleroderma* benefit walk, its largest fundraising event now preparing a fifth edition this July. She is the event's main organizer and logistics specialist.

“The support group has helped me to know what other scleroderma patients are doing for their disease,” said Rivelli, whose scleroderma has had major involvement affecting her hands.

Richard and Denise Bates of Hillsboro also found their role in the scleroderma community through the Portland Support group.

“After being diagnosed with scleroderma, my wife found the Oregon chapter. It has become very important to us, and the support we have received through our tough time was very helpful,” Richard remarked.

His condition with scleroderma worsened to the point he required a double-lung transplant in 2005. Since then, Richard has been elected as the chapter's President and currently serves from the Vice President's chair. Denise also is a member of the group's Board of Directors, and spearheads the chapter's Outreach Advocate campaigns.

“We have learned a lot from the people in the support group,” Richard added, “along with the speakers at seminars and support group meetings. Now we enjoy helping others in the chapter.”

All positions are volunteers in the chapter and support group, which have never had a paid staff.

The long-time former treasurer and current Board member Alice Anson doesn't live with the disease, but came to the group through family ties: “My sister (who has scleroderma) found the support group. That's how I became involved.”

The chapter's current treasurer had a very similar experience. “My sister was Cheri Woo, who had scleroderma. Through her strong commitment and involvement with the Oregon chapter and support group, she hoped to spread awareness to someday find a cure,” Janine Wong said about the late chapter activist who passed away in 2007. “As her sister, I continue to support her cause by being an active member of the chapter.”



Liz Orem-Bedel also found the chapter through the support group. “I seem to remember my rheumatologist, Dr. James Rosenberg, gave me information about the support group,” recalled the Chapter President. “I resisted at first, but (at the urging of my husband Kerry) finally attended my first support group and happily found mostly up and positive attitudes along with the benefit of an informative speaker and the opportunity to talk — not whine and cry — with others who understood what I was going through.

“Guess it's pretty obvious that I just kept coming back. Donna was so friendly and that was huge.”

Orem-Bedel pointed out restorative cures to overwhelming problems aren't very easy to come by: “I really hope that since I can't give any real answers, even after 15 or so years, that maybe I have helped give some positive energy to others. People need to know that most of us find a way to live and manage our lives.”

Stone has raised a family of a son and daughter, and helped with their families, with her husband Peter. As the Portland support group leader for “15 to 20 years,” she advised: “Don't use the Internet too much; it can be a deterrent. There are many conflicts, and you can make yourself paranoid.

“Be your own advocate. Ask questions, questions, questions. Find a doctor you have good rapport with, one who is willing to seek out information if they don't know.

“Also, take someone with you to your appointments. Doctors seem more attentive, and you have someone to share with if you forget details you have just been given. Be sure to share all your concerns since doctors are not mind readers.

“Finally, come to a support group meeting. These are people who have the most experience and knowledge living with the disease.”

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

Symptoms can range from extreme sensitivity to heat and cold to hardened skin to diminished lung capacity and disfigured face and limbs. Scleroderma can be fatal, and there is no known cause or cure.

An estimated 300,000 people have scleroderma, of which 80,000 to 100,000 people in the US have the systemic form of the disease. Scleroderma affects four times as many women as men, usually between the ages 46 to 65.

Page 2 photo: Dr. Lauren H. Kim, a rheumatologist from the Portland Legacy Clinic Northeast, speaks at a support group meeting

Page 3 photo: Dr. Greg Dr. Borstad, a rheumatologist at the Bend Memorial Clinic, speaks at a support group meeting.

<http://www.facebook.com/pages/Oregon-Scleroderma-Chapter/252560183728>

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For more information, visit [www.scleroderma.org/chapter/oregon/](http://www.scleroderma.org/chapter/oregon/) or contact the Scleroderma Foundation Chapter at 503-245-4588, [SDForegon@comcast.net](mailto: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.