

OREGON ANGELS

Chapter President Richard Bates says his new post at this “dynamic organization is a privilege”

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Richard Bates of Hillsboro was unanimously elected President of the Scleroderma Foundation’s Oregon Chapter at the Board of Directors meeting in December.

Bates has lived with scleroderma since being officially diagnosed in 2003.

“I want to thank the Oregon Board of Directors for confirming my appointment as president,” Bates said in anticipation of his two-year term. “Being part

of this dynamic organization is a privilege. I will do my best at being your president.”

Bates (shown at right) follows Liz Orem-Bedel for the chapter’s top post. He had previously served as chapter Vice President.

With the relentless help of his wife Denise, who researched his puzzling and ever worsening symptoms largely via the internet, Richard was finally confirmed as having scleroderma (see continuation on page 2)



8th Annual Cheri Woo Education Seminar

The free seminar has been scheduled for Saturday, March 14 at Linfield College, in the Peterson Hall Auditorium, 2255 NW Northrup, Portland OR.

Keynote speaker will be Karen Gottesman, author of *The First Year: Scleroderma: An Essential Guide For The Newly Diagnosed*

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Chapter Support Group offers “sharing and caring, which gives one a feeling of belonging”

The Support Group of the Oregon Scleroderma Chapter actually predates the organization’s affiliation with the national foundation by several decades.

Donna Stone has helped lead the Support Group for much of that time. *Oregon Angels* recently talked with Stone (at right).

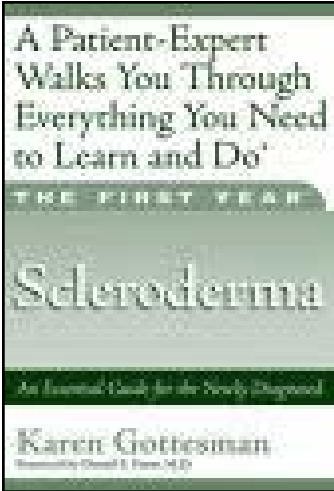
Q. How many attend?



A. 15 to 25 on average. Our mailing goes out statewide and includes SW Washington, about 400 in all, many too far away to attend each meeting.

Q. How do the meetings usually develop?

A. The support group simply assembles with a speaker or an open forum for questions and answers. (see continuation on page 4)



Author Karen Gottesman gives keynote at Cheri Woo Education Seminar



Karen Gottesman

“I am looking forward to meeting you”

Richard Bates, President of the Oregon Scleroderma Chapter

Author Karen Gottesman to give keynote at Spring Education Seminar, March 14 in Portland

Karen Gottesman, author of the well-known book *The First Year: Scleroderma: An Essential Guide For The Newly Diagnosed*, will present the keynote address for the 8th Annual Cheri Woo Scleroderma Education Seminar, 10am-4pm, Saturday, March 14, 2009 at Linfield College, in the Peterson Hall Auditorium, 2255 NW Northrup, Portland, OR.

The annual spring education seminar by the Scleroderma Oregon Chapter & Support Group is free and open to the public. Breakfast and lunch will be provided. Please call (503) 246-0235 or (360) 887-2360 for advance registration, or register the day of the seminar starting at 9:30am.

The annual education seminar is named in honor of the event’s founder Cheri Jo Woo, who died in January 2007 after a long struggle with scleroderma and cancer.

Cheri served the Oregon

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New President Richard Bates believes serving is a “privilege”

rma after many misdiagnoses. His condition became so severe that he underwent a successful double-lung transplant in 2005.

Scleroderma chapter with distinction for more than a decade as a board officer, awareness advocate, fundraising specialist, patient supporter, and education promoter.

She began the first Oregon chapter education seminar in 2001.

Karen Gottesman, author of *The First Year: Scleroderma*, has amassed a wealth of knowledge over the years on autoimmune and autoimmune related diseases. Diagnosed with scleroderma in 1999, she quickly became involved in patient advocacy as well as patient education.

Gottesman currently serves on the Southern California chapter’s Board of Directors for the Scleroderma Foundation and is involved with research projects nationwide.

Bill Thome MSW, a provider of representative services to applicants for Social Security Administration disability benefits, also

will speak at the seminar. A former contract disability hearings reporter for more than seven years, Thome has experienced first-hand the appeals process in thousands of disability hearings.

As a representative, Thome helps disabled clients appeal their denial of benefits. He also regularly provides informational presentations to groups on the subject of securing disability benefits.

Linfield College’s Portland Campus is located in the city’s NW district, adjacent to the Legacy Good Samaritan Hospital and Medical Center.

Parking is free on the street or in Parking Structure #3, between NW Northrup and Marshall with the primary entrance on Marshall between NW 21st and NW 22nd.

(Editor’s note: The seminar originally was announced for Mar. 21 at another venue but was changed due to scheduling conflicts.)

“I am looking forward to meeting you at the Cheri Woo Scleroderma Education Seminar and future support group meetings,”

said Bates. “I hope you are as excited as we are about seminar speakers Karen Gottesman and Bill Thome, and maybe more, we have scheduled this year.”

13th Annual Plant Sale on May 2 & 3 in SW Portland: Chapter's oldest annual benefit

The Oregon Chapter's 13th Annual Benefit Plant Sale is set for Saturday, May 2 and Sunday, May 3, 2009 in the parking lot of Keith's Auto Service Center, 3530 SW Multnomah Boulevard (at SW 35th Avenue), Portland.

The Plant Sale — scheduled for 10am to 5pm Saturday and 10am to 2pm Sunday — arrives just before Mother's Day in order to honor the women and their

families living with scleroderma.

The benefit sale is the chapter's oldest annual fundraiser, one of the two major scleroderma benefit events in the state to raise awareness and funds for research and member support.

"The Plant Sale is always a great fundraiser, and our selection this year is better than ever," former chapter president and plant sale or-

ganizer Liz Orem-Bedel said.

"We always have the event around Mother's Day because scleroderma primarily affects women. It's a way for us to honor these incredible ladies."

For more information, contact 503-246-0235, Orchapter@scleroderma.org or visit www.scleroderma.org/chapter/oregon

"We always have the event around Mother's Day,"

says former president and plant sale organizer Liz Orem-Bedel,

"because scleroderma primarily affects women. It's a way for us to honor these incredible ladies."

4th Annual Stepping Out to Cure Scleroderma Benefit Walk on Sat. July 11 in Multnomah Village

The 4th Annual *Stepping Out to Cure Scleroderma* Benefit Walk is scheduled for Sat., July 11, 2009 at The Multnomah Art Center (7688 SW Capitol Hwy.) and Gabriel Park, Portland.

The event will include entertainment, food, and family activities, in addition to the 2-8 mile-walk (shorter loop also available) through lovely Gabriel Park.

Awards will be given for individual and team categories. Walk participants 14 and older pay a registra-

tion of \$20 (\$25 day of walk) and are encouraged to recruit fundraising sponsors to support their walk.

A T-shirt will be provided to every paid registrant.

Set to begin at 11am, the Family Fun 2.8-Mile Walk-A-Thon benefits the Oregon Chapter of the National Scleroderma Foundation. The money raised will help support the patients and families in the region, increase public awareness, and funding for the many people in our area and across the country

living with scleroderma.

The *Stepping Out to Cure Scleroderma* Benefit Walk is the Oregon Chapter's largest and most visible annual fundraising event.

Call 503-246-0235 to request an advance registration form and pledge sheet, or visit

www.scleroderma.org/chapter/oregon



Walkers enjoy their strides through Multnomah Village.

Don't forget to mark your calendars for July 11, 2009!

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Support Group leader Donna Stone discusses years of “sharing and caring”

Q. What do you feel are some of the benefits of attending the support group?

A. Number one, finding out that you are not alone.

Q. Do you see new people every time, or do the same folks usually attend?

A. We see many of the same. However, there seems to be 2 or 3 new ones each meeting.

Q. What do you feel are some of the benefits of attending the support group?

A. Number one, finding out that you are not alone. Number two, learning about how others deal with their situations.

Q. How exactly did your support group get started?

A. It was started by a lady diagnosed with scleroderma in 1978-79 with the aid of a physician.

Q. Any changes in the group between when you started and now?

A. Not in the basic format. However, the improvement of communications and advancement of treatments help us to be more informative to a larger populace.

Q. Why do you stay involved after all these years?

A. The support group provides a window of sharing and caring which gives one a feeling of belonging. There is an excitement of meeting new patients, as I know what they are going through, having been there myself. []

Support Group meetings held 10 a.m.–noon every second Saturday on alternating months at Legacy Good Samaritan Hospital, 1015 NW 22nd Ave., Portland, OR., in the Wistar Morris Room.

Next regular meeting set for May 9! More information at 360-887-2360 or DonnaPeterStone@yahoo.com