

Oregon Angels

Author Karen Gottesman to advance “proactive patient” care at 8th Annual Cheri Woo Education Seminar on March 14

Inside this issue:

More on keynote	2
Seminar speakers	2
More on Cheri Woo	2
May plant sale	3
July benefit walk	3
Chapter goals	4
Plant sale picture	4

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., adjacent to Legacy Good Samaritan Hospital.

The annual spring education seminar by the Scleroderma

Oregon Chapter & Support Group is free and open to the public.

Gottesman’s keynote, *You Are Your Own Best Advocate: Learning To Become a Proactive Patient*, will speak to her belief that patients need to partner with their healthcare team.

Breakfast and lunch will be provided at the seminar.

Please call (503) 246-0235 or (360) 887-2360 for advance registration, or reg-



Karen Gottesman

ister the day of the seminar starting at 9:30am.

(continued on Page 2)

Cheri Woo Education Seminar continues the work of activist for awareness and research

Seminar Location!

The March 14 education seminar is at Linfield College, in Peterson Hall Auditorium, 2255 NW Northrup, Portland, OR., adjacent to Legacy Good Samaritan Hospital.

Park on the street or Parking Structure #3, between NW Northrup & Marshall; entrance on Marshall between NW 21st & 22nd.

The annual spring education seminar of the Scleroderma Foundation’s Oregon Chapter is named in honor of the event’s founder Cheri Jo Woo.

Cheri (shown at right) died in January 2007 after a long struggle with scleroderma and cancer.

Cheri served the Oregon Scleroderma Chapter with



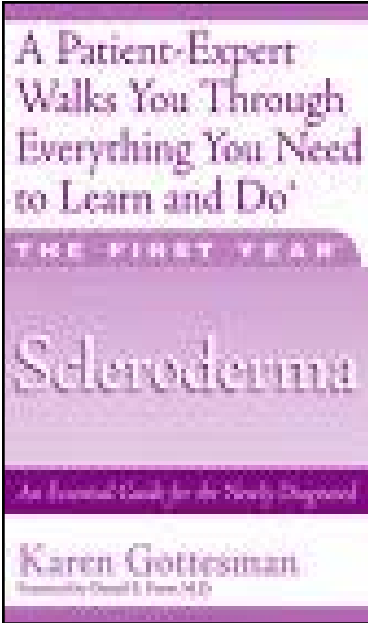
distinction for more than a decade as a board officer, awareness advocate, fundraising specialist, patient supporter, and education promoter.

“Cheri’s passion was to help educate the public about scleroderma in hopes of finding a cure,” recalls her sister Janine Wong, a chapter Board member.

(continued on page 2)

(continued from page 1)

Seminar keynoter Gottesman advocates for patients



Gottesman was diagnosed in 1999 and quickly became involved in fundraising, patient advocacy, and patient education for both the Scleroderma Research Foundation and the Scleroderma Foundation.

Gottesman currently serves as a consultant on drug advisory panels for the Food and Drug Administration (FDA) in addition to running her own business, Smart Patient LLC.

Author Karen Gottesman: **“Patients have described to me how the book has saved their lives.”**

A firm believer in partnering with her healthcare team, Gottesman began to do her own research which ultimately led to the publishing of her book: *The*

First Year - Scleroderma: An Essential Guide For The Newly Diagnosed.

“I have several doctors who give the book to all newly diagnosed patients,” Gottesman told *Oregon Angels*. “Patients have described to me how the book has saved their lives by helping them to get a diagnosis, and helping them become more assertive. Even to switch doctors, too.”

After lobbying on Capitol Hill with the Scleroderma Foundation, she was asked to join the Board of Directors for the Southern California Chapter of the Scleroderma Foundation.

Gottesman has served on the Board for eight years, in many capacities. She served as an Officer of the Board for two years, Education Chairperson in charge of both physician and patient education for another 2 years, and currently serves as Co-Chairperson of a pilot fellowship program at UCLA.

Gottesman has given many workshops on the importance of becoming a proactive patient.

Also the author of *Raising Twins After the First Year* (2007), Gottesman is the mother of fraternal twins.

Benefits advisor and pulmonary speaker round out scleroderma education seminar lineup



Cheri Woo, left, and Dr. Lauren H. Kim at an education event.

A representative for Social Security disability benefit applicants and a speaker on pulmonary hypertension also will present at the Scleroderma Education seminar on March 14.

(continued from Page 1)

Cheri Woo’s life of service honored through seminar

Cheri began the first Oregon chapter education seminar in 2001. Some of the leading scleroderma physicians and patient advocates have participated in the chapter’s spring seminar including Dr. Daniel E. Furst, Dr. Lauren

Bill Thome MSW is a provider of representative services to applicants for Social Security Administration disability benefits. He was a contract disability hearings reporter for more

than seven years.

Megan Liddicoat will speak on pulmonary hypertension. She is a nurse specializing in pulmonary hypertension.

H. Kim, and Dr. Jerry Allen Molitor. This year’s seminar keynote will be delivered by author and patient advocate Karen Gottesman.

After Cheri’s passing, Chapter officers acted to recognize her life and work

by renaming the annual spring education seminar.

“She always said, ‘Knowledge is power,’ ” Wong noted.

“The Oregon Chapter support group was a big part of Cheri’s life. ”

Pre-order/pre-sale system also available for 12th Annual Benefit Plant Sale set for May 2&3 in Portland

Now there's two ways to take advantage of the Oregon Chapter's 12th Annual Benefit Plant Sale.

As before, drop by 10am to 5pm on Saturday, May 2 and 10am to 2pm Sunday, May 3, 2009 in the parking lot of Keith's Auto Service Center, 3530 SW Multnomah Blvd. (at SW 35th Avenue), Portland. Flowers and veggies are available.

In addition, for the first time a pre-order/pre-paid system is in place. Beautiful hanging baskets and 4" geraniums are available for pre-orders.

Please complete the pre-order form on the chapter web site, and return it either by mail or fax along with payment by March 26, 2009.

All 4" plants need to be

pre-ordered by the flat only, and hanging baskets may be ordered in singles.

Orders must be picked up at Keith's Auto on Sat., May 2nd.

For more information, contact 503-245-4588, Orchapter@scleroderma.org or visit www.scleroderma.org/chapter/oregon



Benefit Plant Sale May 2 & 3 !

"A fun way to bring people together" says organizer preparing for July 11 *Stepping Out to Cure Scleroderma* walk in SW Portland



Maria Rivelli (left) and others ready to Step Out for scleroderma research and awareness at a recent benefit walk.

"Seeing everybody walking or just coming out to support the walk, I see new friendships evolve," explained Maria Rivelli, Board member and benefit walk organizer. "We are all here to support each other with scleroderma, and we have a great time doing it!"

Those great times continue at the 4th Annual *Stepping Out to Cure Scleroderma* Benefit Walk 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 available) through lovely Gabriel

Park.

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

"I wanted to get involved in creating *Stepping Out!* here because I like walking and the outdoors," Rivelli, diagnosed in 1992, noted about her motivation. "And I thought this would be a fun way to bring people together who are associated with scleroderma. We are making the word scleroderma more known in our community."

Set to begin at 11am, the Family Fun 2.8-Mile Walk-A-Thon benefits the Oregon Chapter.

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.

"I've had 6 surgeries over the years on my finger tips to debreed the ulcers so they will heal. Scleroderma has mostly affected my hands. I get ulcers on the ends that are hard to heal," Rivelli shared of her life. "I feel very blessed because it could be so much worse."

Call 503-246-0235 for registration and pledge forms, or visit www.scleroderma.org/chapter/oregon

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**BROWSING THROUGH THE GOODIES. GET READY FOR
THE 12TH ANNUAL PLANT SALE MAY 2&3!**

Chapter President Richard Bates outlines goals for 2009

Newly elected chapter president Richard Bates, 53, is a computer systems engineer. Bates and his wife, fellow Board member Denise Bates, reside in Hillsboro.

Regarding his main chapter goals, Bates explained, "We will continue to have education as one of our top priorities, in addition to our plant sale in May and our *Stepping Out* walk in July."

Diagnosed with scleroderma (Systemic Sclerosis Diffuse) in 2003, Bates underwent a double lung transplant in May 2005 due to pulmonary fibrosis and pulmonary hypertension. His symptoms now include Sclerodactyly (thick and tight skin) esophageal dysfunction-GERD, Raynaud's phenomenon, and facial Telangiectasias.

"We will continue to make our support group meetings the best they can be," Bates emphasized. "I have learned so much on how to deal with the day-to-day trials of this disease, not only from the educational speakers we've had, but also from those who have come to our meetings over the last four years and shared their ideas."

In addition to community outreach, Bates also remarked that he is just as open and available to those already within the Oregon chapter family. "While we are doing all of these things, I want to continue supporting our members and all the other scleroderma patients that need help and support. So, please, if you as a member have any questions or need to talk, feel free to contact me."

The new president said he is working hard to increase the volunteer opportunities for the region. "I want to invite more people to volunteer," Bates, a chapter member since 2004, noted. "We are always looking for more volunteers in our fundraising events, as well as new ideas in our Board meetings. So I want to let everyone with some spare time to know that they are very welcome to be a part of our diverse group. I promise it will be a rewarding experience and a great gift to everyone involved."

Bates also has plans for new chapter events. "We are looking to add a Wine Tasting fundraiser for 2009. This promises to be a great opportunity to reach out into the community, and let them know more about who we are and what we are all about."