

Oregon Angels

Dr. Lauren H. Kim at Nov. 14 Portland Support Group Meeting (page 2)

Speakers set for 9th Annual Cheri Woo Education Seminar at Tuality Health Education Center in Hillsboro

Day of free seminar activities planned for Saturday, March 13, 2010



Catherine Markin MD



Anna Bar MD



Justin Elson DDS

Three presenters have been announced for the Oregon Chapter's 9th Annual Cheri Woo Education Seminar scheduled for March 13, 2010 at Tuality Health Education Center in Hillsboro.

The seminar's keynote address will be given by Dr. Catherine J. Markin MD, a specialist in Pulmonary Disease and Critical Care Medicine at Legacy Good Samaritan Hospital in Portland.

Also presenting is Dr. Anna A. Bar, an Assistant Professor of Dermatology and Dermatologic and Cosmetic Surgery at Oregon Health & Science University. (continued on page 2)

Board of directors retreat affirms open-meetings policy

Board directors unanimously voted to retain the current open-meeting policy for the vast majority of future board sessions.

Holding their annual day-long planning retreat on October 17 at Legacy Good Samaritan Hospital, the board of directors for the Oregon Chapter of the Scleroderma Foundation



"Our style is different," President Liz Orem-Bedel (right) said at the annual board retreat, shown with support group leader Donna Stone.

felt the open-meetings policy was a continued benefit to the organization.

"As a general rule, guests contribute," outgoing Treasurer Alice Anson noted. "They don't hold us back."

Chapter president Liz Orem-Bedel began the discussion by noting that all the other foundation chapter board meetings (continued on page 3)

Dr. Lauren H. Kim is the featured speaker at 10am Saturday, November 14, 2009 Portland Support Group Meeting

Dr. Lauren H. Kim MD is the featured speaker at the Oregon Chapter's next Portland Scleroderma Support Group Meeting scheduled for 10am to noon, Saturday, November 14, 2009 at the Wistar Morris Room (first floor) in Legacy Good Samaritan Hospital .

Dr. Kim is a rheumatologist at the Legacy Clinic Northeast who trained at the Scleroderma Center at Boston University School of Medicine for her rheumatology degree, and at Yale Medical Center for her Internal Medicine training.



Lauren H. Kim MD

The Boston University School of Medicine is one of the few centers in the US with physicians and staff dedicated in the treatment and research of systemic sclerosis.

Dr. Kim started a dedicated scleroderma clinic at OHSU Division of Arthritis and Rheumatic Diseases, the only such clinic of its kind in the state.

The support group meetings are always free and open to the public. No advance registration is required.

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Annual Cheri Woo Education Seminar scheduled for Saturday, March 13, 2010 at Tuality Health Education Center in Hillsboro

The annual seminar also is pleased to announce the return of Dentist Justin Elson, DMD, of Hillsboro who had a well received talk on dentistry and scleroderma at the 2007 seminar.

The annual spring education seminar by the Oregon Scleroderma Chapter & Support Group is always free and open to the public.

Breakfast and lunch for the daylong event will be provided with every registration.

For advance registration,

please contact the chapter at 503-245-4588 or orchapter@scleroderma.org

Attendees may also register the morn-



The 9th Annual Cheri Woo Education Seminar is March 13, 2010 in Hillsboro. Some previous attendees above.

ing of the seminar prior to the 10am start.

The annual education seminar is named in honor of the event's founder Cheri Jo Woo, who died in 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.

She began the first Oregon chapter education seminar in 2001.



October board retreat retains open-meetings policy, sets guidelines for new members, and more

were generally closed to guests and visitors.

“But our style is different.”

Chapter Treasurer Janine Wong strongly agreed: “We want people to come and find out more about us.”

Meetings of the chapter’s board of directors are held every other month on the second Saturdays from 10am to noon at Legacy Good Samaritan Hospital. Generally, the attending board members deal with chapter business functions and activities, as well as event planning, fundraising concerns, and more.

However, guests attend nearly every board meeting, including people living with scleroderma

the organization’s support group. The support group meets on alternating months during the same time frame in the same meeting space at the hospital, the Wistar Morris Room on the first floor.

Even the October board retreat hosted some valued guests. Bend Support Group Leader Ann Havelock and her husband Ray made the 3-hour trip to in-

form the board about her new group’s recent activities and plans for the future.

Havelock said after three monthly support group meetings in Bend since August that local doctors are already recommending scleroderma patients to her organization.

She also hoped to host more than one annual fundraiser. Different

event ideas included a ‘50’s Sock Hop, Prom Night, Holiday Fashion Show, and a Dance

Marathon.

* Board directors discussed



“Guests contribute” to regular chapter board business and planning meetings, Alice Anson (standing) said.

possibly adding up to three new board members in the coming months.

In order to do so, a number of assets criteria were developed for any prospective board members: attend at least two board meetings prior to member approval, possess energy for the chapter’s mission, be an upbeat and positive personality, willing and able to participate and provide action for chapter events, and have a willingness to learn.

* Board members also approved creation of an informational-only chapter physicians referral list. The listed physicians will have experience with scleroderma patients, with the list to include a wide



Bend support group leader Ann Havelock (left) discusses activities with board members Maria Rivelli, Lawrence Maushard, Donna Stone and Liz Orem-Bedel.

who find the chapter via the Internet hoping to connect with

Rheumatologist Greg Borstad hosted by the Central Oregon Support Group Meeting in Bend

by Ann Havelock, Central Oregon Support Group Leader

Rheumatologist Greg Borstad of the Bend Memorial Clinic was the featured speaker at the Central Oregon Scleroderma Support Group Meeting on October 8, 2009.

The support group meeting was attended by five people living with scleroderma, two spouses and certified hand therapist and assistant group leader Trish Dyer.

Dr. Borstad explained in detail Reynaud's phenomena as it applies to scleroderma patients. He presented computerized images of affected hands, from mild to severe cases, explaining the difference between primary and secondary Reynaud's.

Trish Dyer provided handout sheets with information on how to avoid flare-ups and how to protect hands and feet when exposed to cold air or touching cold items.

She shared how important it is to use the best moisturizer, with the ingredient

squalen, for skin care.

Everyone at the support group



Dr. Greg Borstad makes a point at the October Central Oregon Support group meeting in Bend.

meeting was extremely pleased with Dr. Borstad and Dyer's presentations, saying they learned quite a bit in an enjoyable fashion .

The Central Oregon Scleroderma Support Group meets the second Thursday each month at the Bend Memorial Clinic (upstairs in the Physicians Lounge), 1501 NE Medical Center Drive, Bend, Oregon 97701.

Next meetings are
5:30pm, Thursday, Nov. 12, 2009 and
5:30pm, Thursday, Dec. 10, 2009.

Support Group Leader: Ann Havelock,
541.480.1958, mzann@bendbroadband.com

Support Group Coordinator: Trish Dyer,
541.330.0215, cht@bendcable.com

The attendees all said that they would like the support group to host guest speakers at future meetings in order to

become better educated and more knowledgeable about scleroderma.

Most of us are frustrated and upset because we were given a diagnosis and medicated without detailed explanations, discussions or counseling about scleroderma.

As a support group leader, I recommend we get involved and be responsible for learning all we can about this disease to help raise awareness and generate funds for more research.

The more people living with scleroderma that we have involved in our efforts, the more attention we'll get from the media, and more research money we'll be able to raise.

We need to make our voices heard by *everyone* in order to get positive results, and especially to help newly diagnosed patients. []