

# *Oregon Angels*

## **Chapter raises awareness issues with Portland Mayor Sam Adams**



Chapter Member Fay Maushard and Portland Mayor Sam Adams hold a conversation about scleroderma and its complications at City Hall.

Oregon Chapter representatives had the opportunity to personally raise scleroderma awareness issues with a big city leader when they met privately with Portland Mayor Sam Adams earlier this month at City Hall.

Chapter President Liz Orem-Bedel and Member Fay Maushard held conversations for approximately 20 minutes with Mayor Adams and his Community Liaison Jane

Ames on Monday morning, March 1 in the warmly appointed and spacious 3rd-floor corner visitors' lounge immediately adjacent to the mayor's modest personal office.

"It was a great feeling to be able to share my scleroderma patient's voice with Portland Mayor Sam Adams," Maushard

said. "He made me, as a Portland resident, be so proud of living in a city lately governed by leaders with such character. The first com-



Chapter President Liz Orem-Bedel shares a point of awareness with Mayor Sam Adams on Monday, March 1 in downtown Portland.

passionate and caring mayor I met back in **(continued on page 4)**

## **Preparations set for 9th Annual Cheri Woo Education Seminar, March 13**

There is still time to register, even on the day of the event, for the chapter's 9th Annual Cheri Woo Scleroderma Education Seminar on Saturday, March 13 at the Tuality Health Education Center in Hillsboro.

The free event, breakfast and lunch included, is Oregon's largest public scleroderma session designed to inform and educate the attendees and



**Dr. Catherine J. Markin**

wider public about the latest medical information regarding our autoimmune disease.

"It is going to be very busy with keynote speaker Dr. Catherine Markin on *Lung Disease in Systemic Sclerosis: New Insights and Treatment Options* leading the presentations," seminar organizer **(continued on page 2)**

(continued from page 1)

## Preparations set for 9th Annual Cheri Woo Education Seminar, Mar. 13



**Dr. Anna A. Bar**

Denise Bates said. “We will all learn a lot on Saturday.”

Bates, a Board member and the chapter’s Outreach Advocate, explained that early registrations were strong, the food had been ordered, and the attendees information packets were assembled and ready to go.

“It should be a great learning and sharing time.”

Doors at the Tuality Health Education Center, 334 Southeast 8th Avenue in Hillsboro, will open at 9:30am for free on-site registration and a continental breakfast.

The seminar kicks off at 10:00am with an official welcome by Donna Stone, long-time chair of the chapter’s support group, operating in continuous service to the community since 1981.

The first presentation begins immediately afterwards by Dr. Anna A. Bar, Assistant Professor of Dermatology and Dermatologic and Cosmetic Surgery at Oregon

Health & Science University. Her seminar topic is *Cutaneous Manifestations of Scleroderma and Laser Treatment*.

With a 15-minute break between speakers, including Q&A interactions with the audience, the keynote presentation by Dr. Markin is scheduled for 11:25am.

Following an on-site lunch of about one hour, the seminar’s final presentation is set for 1:30pm by Justin Elson, DMD, of



Gentech Dentist Hillsboro. He will speak on *Scleroderma and Oral Health*.

Chapter President

Liz Orem-Bedel will wrap up the seminar with brief concluding remarks at 2:30pm.

The annual spring 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 offi-

cer, awareness advocate, fund-raising specialist, patient supporter, and education promoter.

As noted, on-site free registration is available, though advance registration is encouraged. Please register by calling 503-245-4588 or using the online form at [http://](http://www.scleroderma.org/chapter/oregon/2010EdSem_Reg.htm)

[www.scleroderma.org/chapter/oregon/2010EdSem\\_Reg.htm](http://www.scleroderma.org/chapter/oregon/2010EdSem_Reg.htm)

“I have been amazed by how many people have preregistered and how early this process started,” Orem-Bedel remarked.

“It’s a testament to the work by our all-volunteer staff and especially to the incredible line-up of speakers we have again this year. For the 2010 edition, we’re very fortunate to present doctors Markin,

Bar and Elson, all leaders in their fields.” []



**Justin Elson, DMD**

More background on each speaker is available in the press release “Spring seminar speakers announced” at

<http://www.scleroderma.org/chapter/oregon/pdf/2010/SFOSeminar2010.pdf>



# Bend support group hosts Pharmacist Kyle Mills, PharmD, BCPS

by Ann Havelock

We had a great turnout on Thursday, Feb. 11, 2010 to hear our guest speaker Kyle Mills, PharmD, BCPS.



tended the meeting because his mother from the Burns area has scleroderma.

Colby and the rest of his family want to learn all they can about scleroderma in order to be as supportive as possible for their mother. He had sent his mother the article the *Bend Bulletin* daily newspaper wrote about my situation last fall. It described her jour-

search on the current scleroderma funding bills before Congress, noting one has been presented, the other put on the back burner due to federal Health Care Reform. But he also sees no opposition concerning these bills for passage.

Colby also stated that his mom absolutely needs to attend our group as we are so positive and supportive.

Yes!

Everyone came prepared to take notes and asked questions concerning not only prescribed medications but over-the-counter medications and supplements.

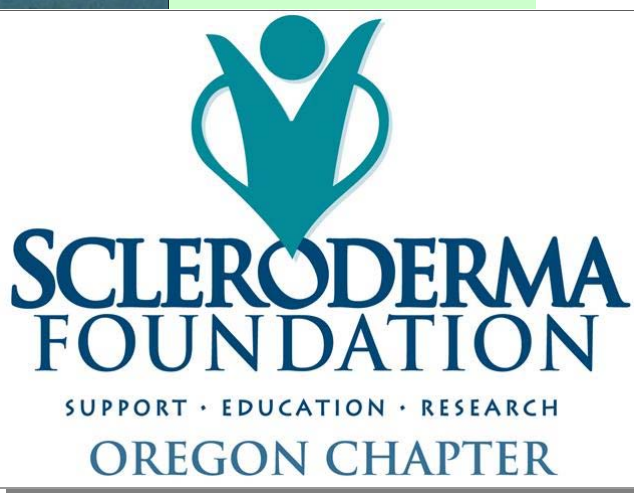
The guest speaker obviously put a lot of time and effort into his presentation, and we are now better informed on the medications we take.

Dr. Mills is the pharmacist for the Bend Memorial Clinic, and also a Board Certified Pharmacotherapy Specialist.

He explained the more educated and knowledgeable we are about our medications — and how they affect us — can make a difference in our health.

It was a very interactive group during the presentation, and we immediately invited Dr. Mills back for more in 2011.

After Dr. Mills, we turned our attention to a young man who at-



ney too.

She has been traveling to Seattle for treatment and will now apparently consider changing to a rheumatologist here in Bend, he said.

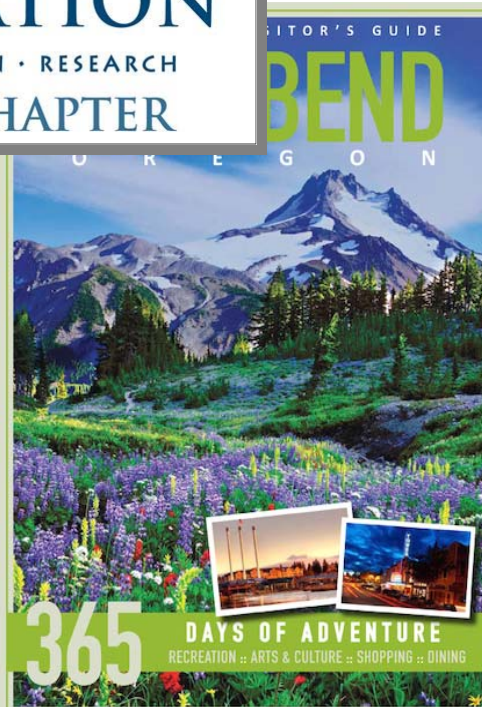
Colby was impressed with our group and will help his mother attend the next monthly meeting on Thursday, March 11.

Another exciting thing about Colby is his position as a political aide to US Congressman Greg Walden (R)! Colby did re-

He said during Dr. Mills presentation that he observed everyone's hands and saw his mom's hands. Colby would like her to see a hand therapist for evaluation.

We also had a new member, Barb Eager from the Powell

Butte area, who was diagnosed about 10 years ago. []



*The Bend Bulletin article Ann mentioned in her story is still available at*

[http://](http://www.bendbulletin.com/apps/pbcs.dll/article?AID=/20090924/NEWS0107/909240313/1041&nav_category)

[www.bendbulletin.com/apps/pbcs.dll/article?AID=/20090924/NEWS0107/909240313/1041&nav\\_category](http://www.bendbulletin.com/apps/pbcs.dll/article?AID=/20090924/NEWS0107/909240313/1041&nav_category)

(continued from page 1)

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2007 for similar scleroderma awareness issues was the previous mayor, Tom Potter. He was really concerned about human life and dignity, and we again have another concerned and compassionate leader in Sam Adams.”

President Orem-Bedel felt likewise. “Mayor Adams took a lot of time with us and was very interested in our quest for awareness.”

Prior to meeting the mayor, Maushard and Orem-Bedel were engaged by Community Liaison Jane Ames who had obviously done some homework. “Adams and Ames were wonderful,” Orem-Bedel added.

Like many people living with the disease, Maushard said that all too often people tend to tune out whenever the talk turns to a rare malady like scleroderma. That was certainly not the case with Mayor Adams.

“He was incredibly friendly and generous in his time and listening to my detailed conversation about the nature of the disease and its complications,” she explained.

“I spoke about patient needs such as increased costs for extra heating needs, the continual need for more research dollars and always trying to get the word out about awareness by patients and civic leaders.”

Those words and others by Maushard and Orem-Bedel did not fall on deaf ears.

“Get me a letter together, and I’ll see what we can do about utility discounts for heat and water,” Adams offered.

Those apparently were not just kind words uttered during a meeting with constituents. A follow-up message of thanks from the chapter

was personally answered by an email from Mayor Adams: “It was my pleasure! I look forward to pursuing utility rate relief.”

Since the meeting, the chapter has received input from a California Foundation chapter which has enjoyed utility rate discounts for many years. The next step by the Oregon Chapter is to write a letter outlining the medical and practical needs for utility rate breaks for scleroderma patients and forward the document to Mayor Adams. That letter is expected to be

in City Hall during the second week of this month.

“In City Hall the temperature was normal, but as a patient with Raynaud’s phenomenon, I needed to have my gloves on, at least one on all the time because it was cold for me,” Maushard noted. “But I felt at ease in the presence of the mayor with my gloves on. At first I was a little worried about it, and took one glove off. Later I put it back on because the friendly environment and understanding put me at ease.

“Also I talked to him about Raynaud’s and how each patient was affected by so many different symptoms. How everyone living with scleroderma is different.

“It was important too that he listened about how scleroderma can affect connective tissue in every internal organ, not only the visible skin that people see and know about.” [ ]

*For more photos from the City Hall meeting with Portland Mayor Sam Adams, please see the chapter’s Facebook page at*

<http://www.facebook.com/album.php?aid=153853&id=252560183728&ref=mf>

