

**Oregon chapter focused on awareness, fundraising with 4th annual “Stepping Out to Cure Scleroderma” event**  
**More participants than ever at July 11 benefit walk in Portland !**

The largest number of registered walkers and volunteers, outstanding celebrity participants, committed sponsors, and the best news coverage to date were all hallmarks of the 4th Annual “Stepping Out to Cure Scleroderma” benefit on July 11 in Portland.

The event drew a record 156 registrants compared to 135 in 2008!

Total funds raised this year were not available as of press time due to donations and expenses still coming in. A final accounting is not expected until the last quarter this calendar year. In

2008, the walk cleared about \$18,235.

“I think the walk went very, very well,” Chapter President Liz Orem-

walkers and their supporters. That’s a good problem to have.”



**Fun, friends, and family** made the 4th “Stepping Out to Cure Scleroderma” benefit in Portland a big hit. Carolyn Poutasse and Andrew Wagner led the way.

The person who brought in the most money by the day of the walk was Melissa Hammond with \$1,050.00. Janine Wong came in a close second at \$1,000.00.

“We will probably raise a bit less than last year due to a decrease in corporate giving in these tough economic times,” Board member and event organizer

Bedel said. “We actually ran out of table space, though not chairs, at the Art Center assembly spot because of the growing number of

Maria Rivelli explained. “But just as importantly on the up side is that *Stepping*

**(continued at page 3)**

**“An excellent time to greet old friends and make new ones”  
at the Scleroderma National Conference, *Gateway to Hope*, July 17-19 in St. Louis  
... by Chapter President Liz Orem-Bedel**

Every year the Scleroderma Foundation, Oregon Chapter is proud to send three representatives to the organization’s national leadership conference. The 2009 edition, *Gateway to Hope*, was held July 17-19 in St. Louis, Missouri.

This year the national office invited the president, vice president (Richard Bates) and treasurer (Maria Rivelli) stepped in for Janine Wong) of each chapter to join them for a full day of leadership education.

This special day is a non-stop event with many educational sessions going on at the same time.

It’s also an excellent time to greet old friends and make new ones, a time to both catch up with other chapter’s activities and find out what the National office is doing and what changes are coming our way.

On the administrative side, apparently this year the IRS has changed a couple items for nonprofit groups.

But back to the good stuff!

My first session was given by Mary O’Neil, a leadership consultant for some very big corporations like



**Oregon represented at 2009 National Scleroderma Conference — Chapter President Liz Orem-Bedel (second from left), Board Member Maria Rivelli, and Vice-President Richard Bates pose with Simon Mittal, MD of Owatonna, MN (left) at the Foundation’s “Gateway to Hope” Conference July 17-19 in St. Louis.**

Xerox, McDonald’s and Texaco. Mary also lives with scleroderma. Mary e-mailed each of us a personality test to be completed before we arrived and had results ready when we entered the room.

Her seminar was entitled “It’s not all about me.” In it, we had a chance to explore ourselves and more importantly to explore the personalities of others.

All the seminar attendees sitting in the room discovered how important it is to have a little of as many different personalities as possible on a board or at an event in order

to work in harmony and create the balance needed to accomplish all projects.

It was a great way to start the day.

Then came Saturday and Sunday with the general conference for everyone, a continuing education offered to all. Included were some familiar topics, as well as some new ones. I love learning about the latest in the scleroderma world!

This year an important national legislative bill was introduced, and it needs our help in order to pass. It’s

**(continued on page 4)**



Fox 12's Debra Gil (left in event t-shirt), Blaze of the NBA Portland Trail Blazers, and friends!

(continued from page 1)

*Out to Cure Scleroderma* is becoming more well known: we had Fox 12 news with Debra Gil attending, along with Blaze, the official mascot of the NBA Portland Trail Blazers.

“More local public awareness for people living with scleroderma,” Rivelli added, “is a big reason we’re all here.”

In fact, Portland television station KPTV Fox 12 aired newscasts of the event no less than five separate times over two days, including the 5:00pm Weekend Evening News, and the 10:00pm Late News, both on the day of the walk.

A week prior to the event, Portland TV station KATU Channel 2's *AM Northwest* hosted a chapter awareness team and broadcast information about the 4th annual benefit.

The team that raised the most money by the day of the walk was Team Marty at \$2,140. The second

place group was Team Ken Landreth at \$1,280.

As part of the ongoing efforts to elicit feedback from the participants, people were asked to fill out questionnaires once they completed the 2.8-mile or shorter loop walk routes.

Some of the replies included, “The walk was just right!” and the Children’s Corner activities were “great.”

One person said they most enjoyed the opportunity for “friends and exercise,” while another wrote the chapter’s scleroderma events “are always well organized.”

Sponsors for the walk include Portland Old Boys Breakfast Group, DiversiForm, Old Spaghetti Factory, Rose’s Restaurants, The Vitamin Shoppe, Trader Joe’s, Cash and Carry, Olive Garden, Noah’s Bagels, Extended Stay of America, Dr. Michael Van Allen, Merrill Lynch, Columbia Empire Meat, Lavender Bleu, Starbucks, Annie Blooms, and Thinker Toys.



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**Stretch for Success!** — Liz Orem-Bedel leads the group fronted by Gaye Moye Jacobs (seated) in a few stretching exercises prior to the 4th Annual “Stepping Out to Cure Scleroderma” benefit. ( event photos by Janine Wong, Fay Maushard)

(continued from page 2)

## **Oregon chapter again sends representatives to national conference**

the H.R. 2408 bill, cited as the “Scleroderma Research Act,” which is in the process of being introduced both to the US House of Representatives and the Senate.

It reads, in part, “To expand the research and awareness of the National Institute of Arthritis and Musculoskeletal and Skin Diseases, and the Centers for Disease Control and Prevention with respect for Scleroderma.”

*This is the first time a bill is designating money specifically for scleroderma research and not be lumped in with other diseases.*

We’re talking about a sum of \$2.5 million annually for the years 2010, 2011, and 2012. This is exciting!

In order to help this along, I now have a copy of a non-partisan letter requesting your congressperson and senators sign our H.R. 2408 bill as co-sponsors.

The letter is simple and direct in its request, and ready for your signature. The good news is there is only a small portion for you to fill in and the National office will do the rest.

I will have copies of the letter at the September Support Group meeting. In the meantime, if you are unable to

join us in September and cannot wait another moment to sign this important bill, simply go to [www.scleroderma.org](http://www.scleroderma.org), and click on “Become an Advocate”.

Or you can always call me (503-245-4588), e-mail [ORchapter@scleroderma.org](mailto:ORchapter@scleroderma.org), and I will gladly send you a copy of the letter.

Please join me in this effort to further the research and broaden awareness of this disease.

I hope you all are well and wish the best for you and your loved ones. [ ]