

Oregon Angels

“The Plant Sale is my *passion!*”

Year after year, weekend event raises funds and awareness

Inside this issue:

More on Plant Sale	2
Seminar wrap	3
More on the Walk	3
Another perspective	4
Walk photo	4
Chapter contacts	4

May 9

Support Group Meeting

Acupuncturist Edward Chiu, LAC, DAOM is set to speak at 10am Sat. May 9 at Legacy Good Samaritan Hospital, Wistar Morris Room, 1st floor.

More info. at Donna Stone, 360-887-2360 donnapeterstone@yahoo.com

As a primary founder of the Oregon chapter's longest running benefit project, Liz Orem-Bedel explained that the origins of the annual spring Plant Sale focused on the group's *raison d'être*.

“It was pretty straightforward,” the chapter's vice president (shown at right) said. “somehow combine fundraising with awareness, and we looked for an event to do both, that people would want to return to.”

As a result of those efforts, people from the surrounding Multnomah Village and beyond are ready to return for the *twelfth straight year* to

the parking lot of Keith's Auto Service Center, 3530 SW Multnomah Blvd. (at SW 35th Avenue), Portland, on May 2 and 3, strategically timed the weekend prior to Mother's Day.

“Donna Stone, Maria Rivelli, myself and our spouses have all been active in the chapter. We all jumped right in and became very involved in the Plant Sale from the start.”

This year's edition is set for 10am to 5pm on Sat., May 2 and 10am to 2pm Sun., May 3. A generous and healthy variety of flowers and vegetables will be available.

(continued on page 2)



Start your fundraising web page now for the 4th Annual *Stepping Out to Cure Scleroderma* Benefit Walk, July 11

People are starting to prepare for the Oregon chapter's 4th Annual *Stepping Out to Cure Scleroderma* Benefit Walk on Saturday, July 11, 2009



in Portland.

One of the fun ways to participate now is by starting your own fundraising web page. Just visit the chapter web

(continued on page 3)

(continued from page 1)

Plant sale continues to raise funds and awareness year after year

“We always have the event around Mother’s Day because scleroderma primarily affects women,” Orem-Bedel noted. “It’s a way for us to honor these incredible ladies, around a traditional holiday for women.”

As for the longevity of the event, Orem-Bedel said it comes down to her personal interest as a horticulture hobbyist. “It’s my love of planting and gardening, growing both food and flowers. Sometimes you need peace of mind, getting a spade, digging in the dirt, growing something new. For some of our board members, they’re really passionate about the Walk. I’m really passionate about the plant sale.”



Plant sale organizers Donna Stone (left), Liz Orem-Bedel, and Maria Rivelli ensure awareness and fundraising via the popular plant sale.

A big part of the success to date behind the plant sale has been its location and site benefactor in Keith’s Auto Service Center at SW 35th and Multnomah in the busy heart of Portland’s Multnomah Village.

“We’ve always been at Keith’s Auto. He has been extremely generous to the chapter, letting us use his parking lot in a place that’s seen by a lot of traffic,” Orem-Bedel explained.

That heavy traffic strategy has

paid off. “People look forward to the plant sale. Every year they say, ‘We’ve been waiting for you!’ So we’re very happy with the response from the neighborhood over the years.”

Of course, the plant sale is about much more than raising money.

“It’s about awareness as much as fundraising. We always give out *lots* of information. In this regard, I think we’ve succeeded.

“People always ask, ‘What is scleroderma?’ The plant sale has always been an opportunity to talk about our disease.”

Talking about scleroderma is something Orem-Bedel has been passionate about for a very long time. She recently turned over the chapter presidency to Richard Bates after

serving six years as head of the Oregon group.

“I was diagnosed at age 44,” Orem-Bedel remarked. “Now I’m 60. At first it was horrific, painful and scary because nobody knew what to expect, what to do about it. They didn’t have anything that would work, no medications.

“Now I’m stable. On my hands, the skin is so tight; the fingers are curled in and can’t flex out. They cannot be straightened out.” The conditions of her hands aren’t the only manifestations from the disease. “The internal problems I also deal with on a daily basis, but I’ve learned to deal with them.”

As the plant sale remains a mainstay of the chapter’s outreach

efforts, Orem-Bedel remains hopeful about the future.

“I really believe we’re going to find help. I don’t know about a cure, but it’s really important for everyone to do what we can.”

The 12th Annual Plant Sale offers hanging baskets to Calla lilies to Petunias and much much more. Our suppliers include Al’s Nursery, Fessler’s Nursery, Egan Gardens, Clackamas Greenhouses, Blooming Baskets and Keyser’s Nursery. We’re proud to work with them.

Author Karen Gottesman teaches proactive patient care at 8th Annual Cheri Woo Education Seminar in Portland hosted by Oregon chapter

"I'm going to look for a new doctor on Monday" was one of the strong reactions keynote speaker Karen Gottesman received at the 8th Annual Cheri Woo Education Seminar hosted by the Oregon chapter on March 14 at Linfield College in Portland.

Additional comments at the seminar like "You made me realize I'm not getting the care I need" and "Your book was a life-saver" only reinforced the importance of providing guidance and support to *all* types of patients, Gottesman said afterwards.

Noted author and patient advocate Gottesman presented *You Are Your Own Best Advocate: Learning To Become a Proactive Patient* on her belief that patients need to partner with their healthcare team.

"It was especially nice to know there were some new faces in the crowd. Hopefully, they will have learned — either through my book or my talk — just how important it is to become a proactive patient, and how best to get the care they need," remarked the author of the well-known book *The First Year: Scleroderma: An Essential Guide For The Newly*



Keynote speaker Karen Gottesman & chapter President Richard Bates

Diagnosed.

"We sold a lot of books, and we had a lot of new people, or people we haven't seen in a long time," Denise Bates, seminar organizer noted. "I would like to thank everyone who came and all who helped."

In addition to Gottesman, the seminar presented Bill Thome MSW on Social Security Administration disability benefits and Megan Liddicoat, a nurse specializing in pulmonary hypertension.

Approximately 50 people were on hand to hear Gottesman's presentation as she implored them to not "settle for someone who's not giving you the best treatment!" Gottesman also



Seminar attendees participate in the 8th Annual Cheri Woo Education Seminar held March 14 in Portland

stressed the real-world aspects of American medical care. "Your rheumatologist should be local and act as a quarterback for you. However, don't fall in love with him or her until you've made sure that doctor is on your insurance plan. If not, that's a deal breaker."

(continued from page 1)

Start your own Walk web page now for 4th Annual Stepping Out Walk Sat., July 11 in Portland

site or go directly to <http://www.firstgiving.com/scleroderma-oregon>

Once you've created your web page, you can direct friends and family there as an easy way for them to support you

and the efforts of everyone involved to raise awareness and funds for people living with scleroderma.

In fact, two people have already created web pages for the walk.

Please help and support Nancy Rorick at <http://www.firstgiving.com/nancyrorick> and Taneesha Heck at <http://www.firstgiving.com/taneeshaheck>.

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The 4th Annual Stepping Out to Cure Scleroderma Benefit Walk is set for Sat., July 11 in Portland. Register now! : <http://www.scleroderma.org/chapter/oregon/2009walk.shtm>

Another perspective: Additional commentary generated by the 8th Annual Cheri Woo Education Seminar

One of the attendees at the 8th annual spring education seminar was Maria A. Pfeifer, coordinator for *My Life Works Today! A Living, Learning and Lupus Network* headquartered in Beaverton. Her experience at the seminar motivated Pfeifer to share her thoughts on the blog she maintains at <http://www.mylifeworkstoday.com/blog/>.

The following are excerpts from her recent posting about the annual scleroderma education event.

“The local Scleroderma Chapter held their 8th Annual Cheri Woo Scleroderma Education Seminar offering specific information and resources for those living here with this autoimmune disease. As little as we hear about lupus, communities hear even less about scleroderma.

At the seminar, the chapter offered informational materials, speakers

for different aspects in managing the illness, opportunities for Q&A with the panel and fellow participants, breaks between presentations, a free boxed lunch and a great opportunity to meet, speak with and feel part of a strong, supportive community.

I sat in the audience and felt as though I could have inserted the word “lupus” every time scleroderma was mentioned.

A poll of the seminar participants showed that they were pretty familiar with the illness, but eager to hear about anything new pertaining to research, clinical trials and recommended doctors — especially participants who were from more rural communities.

As those of us with lupus living outside the Portland-metro area and struggling to find rheumatologists within 50 miles of

where we live, the seminar participants are fighting the same battle.

Living with an autoimmune illness that is difficult to diagnose, treat and sometimes even see leads us to seek out our own corners in which to stand — either to categorize ourselves in one way or to avoid being seen, depending on the person.

However, what MLWT is trying to bring to the table locally is the fact that we share so much more in common, and the dividing lines, labels and ‘causes’ tend to isolate and minimize the impact we all are trying to make on our communities’ understanding.

The phrase ‘united we stand, divided we fall’ applies very effectively to building bridges and resources for all living with autoimmune diseases -- of which there are an estimated **50 million Americans** with at least one autoimmune illness.”