

Debra & Blaze are Back !

The Oregon Chapter is proud to announce that celebrity guests Debra Gil, anchor/reporter with the Fox 12 News Team, and Blaze the Trail Cat, official mascot for the NBA Portland Trail Blazers, will join us for the 5th Annual *Stepping Out to Cure Scleroderma* benefit walk on July 10, 2010 in Portland!

Their appearance marks the second straight year that Debra and Blaze will help make the benefit walk the chapter's largest and most visible annual fundraising and awareness boosting event.

As the walk's Media VIP, Debra



Debra Gil (far left) & Blaze are back this year!

Gil will address the assembled striders just prior to the 2.8-mile 11am walk at the Multnomah Arts Center, 7688 SW Capitol Hwy. Her work and reporting last year resulted in no less than 5 separate airings of a walk news feature over a two-day period on Portland's Fox 12 TV.

Blaze was an incredible and exciting feature of the 2009 walk, meeting and greeting everyone, especially the kids, before the start of the event. His presence this year will again make the walk a great family fun experience.

Register now for the walk at <http://www.firstgiving.org/scleroderma-oregon>

"We are both anxious to do what we can to improve the situation." Peter & Erika Hall give walk sponsorships, donate equipment and more

"When Erika was diagnosed with scleroderma, as a nurse she wanted to know as much as she could find out about it, and the foundation chapter seemed to be the best way to get the knowledge," Peter Hall explained about finding the Portland-based non-profit. "This took place about four years ago, and we have kept attending the meetings."

In addition to the support group sessions, the married couple also began attending chapter semi-



Peter & Erika Hall

nars, other events, and more. "We saw how little was known about the disease," noted the Manchester, England native, "and we felt that if we could help get the awareness improved we should do what we could to help."

Erika, originally from Germany, lives with a scleroderma condition described as "miserable." She suffers a lot of pain, often at night, resulting in severe sleep deprivation, and constant
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Support Group Leader in the Spotlight: Donna Stone explains "How to Best Serve Your Support Group Members"

(this article originally in the March/April 2010 issue of "SF- Direct Connection")

Donna Stone was diagnosed in 1979 with scleroderma at 40 years of age. Despite the textbooks that touted a "seven-year life expectancy" for individuals with scleroderma, Donna could not abandon the hope of seeing her two children, then ages 10 and 12, grow into adulthood.

Two years later and still committed to her goal, Donna joined her first independent scleroderma support group. There, Donna met others like herself, who were battling the disease. It was not long before Donna offered to become leader of her support group in 1991.



Now 19 years later, Donna continues to act as the support group leader for the Oregon Chapter.

At 71, she's long outshined her initial goal of making it through her children's teenage years. With all the wisdom she has gained as both a scleroderma patient and a support group leader, Donna shares the following tips on how to best serve your scleroderma support group members.

"Communicate Between Meetings:
It's important to keep a pulse on the thoughts and feelings of your support
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Peter & Erika Hall provide walk sponsorships, donate equipment & more

use of pain killing drugs, few of which give relief.

"It makes us very unhappy to see how little is known about disease, and we are both anxious to do what we can to improve the situation," Hall said.

"We don't have a lot of money, but we do have certain favorite charities, one of which is the Scleroderma Foundation. There are a couple of others we support: 'Smile Train' helping kids with cleft palates, and Erika, the animal lover, supports the ASPCA and PETA"

The Halls have specifically decided to help, in part, by supporting the chapter's largest annual fundraising effort, the "Stepping Out To Cure Scleroderma" benefit walk. Its 5th edition is scheduled for July 10th in SW Portland.

Each year the couple put up \$250 to sponsor the Portland Old Boys Breakfast Group. This group was

founded in 1992 by several husbands of the women who were members of the Daughters of the British Empire. The group was formed and the membership has fluctuated, and at the present there are about 50 members,



Peter & Erika and Blaze at 2009 walk

mostly retired 70 year olds, but there are some "kids" in their late 40s and 50s.

The group meets on the last Friday of each month at the Marriott in Tigard at Carman Drive and I-5 for breakfast at 8:30am followed by a talk by a member or a guest speaker. "We try to encourage individual members to

register for the walk," Hall noted. "Some will donate \$50, some will give the basic \$20 donation. The group doesn't pay anything to sponsor the walk, mainly because they have never been asked. Unlike cancer, which is a well-known disease, scleroderma is a low-profile disease, and I am happy to shoulder the largest part of the donations for this event."

The giving doesn't stop there.

The Halls recently forwarded \$330 to the Foundation, money that was generated by a cook-book sales project of the Portland Old Boys Breakfast Group.

Through their regular participation in chapter events, Peter and Erika also noticed a particular need that required some attention. Last year they donated a new \$400 mobile sound system that made a big improvement over the old system that was available at the time. []

Nutritionist Lori S. Brizee MS, RD, LD, CSP leads May Support Group in Bend

by Ann Havelock

For its May 13 meeting in Bend, Central Oregon Scleroderma Support Group welcomed guest speaker Lori S. Brizee, MS, RD, LD, CSP, a certified specialist in pediatric nutrition, also certified in pediatric and adolescent weight management nutrition services for infants, children, adolescents and adults.



Lori Brizee

We had another great turnout of group members, this time eager to learn something about nutrition for scleroderma patients.

It had been frustrating not having a nutritional guide that might help to better manage our daily diets, mostly due to the unknown causes behind scleroderma.

Our guest speaker, in fact, had little previous experience with scleroderma patients and therefore did quite a bit of research before her presentation, putting in a lot of time and effort on this project.

During her research, Brizee actually introduced scleroderma to other medical professionals who had not heard of the disease. So our meeting, before we even started, became a great way to further help raise the local medical community's awareness of the scleroderma.

According to her workplace web site at Central Oregon Nutrition Consultants, Brizee's 25 years of

experience spans working with premature infants in a neonatal intensive care unit to children and adults with special diet needs to weight management.

She spent an hour explaining issues and answering questions on our individual challenges of digestion and nutritional needs. At the meeting, she described problems with scleroderma that can cause poor nutrition, including:

- * Difficulty preparing foods and getting food to mouth, due to hardened skin on fingers and hands.
 - Get kitchen utensils with thick rubber handles.
 - Find cups, mugs, water bottles that are easiest to pick up.
 - Buy pre-cut meat, vegetables and fruits for easier meal preparation.

- * Difficulty getting food and liquid into mouth due to hardened skin around mouth.
 - Use a water bottle allowing you to squirt liquid into the mouth.

- Puree or mash foods with liquid making them easier to get into your mouth.

- * Difficulty chewing and swallowing due to dry mouth (Sjogren's syndrome)
 - Sip on water throughout the day.
 - Chew sugar-free gum or suck on sugar-free candy to stimulate saliva.
 - Use over-the-counter dry mouth products (e.g. Biotene mouthwash and oral gel).
 - Ask your doctor for a prescription for

Evoxac Salagen.

- * Difficulty moving food through the esophagus due to weakened muscles and/or scarring.
 - Eat slowly, chew food thoroughly.
 - Eat moist foods rather than dry foods.
 - Drink fluids in between bites of food.
 - Use blender on foods with broth or other liquid to help them go down easier.

- * Gastro-esophageal reflux disease (GERD)
 - Limit foods that increase stomach acid (alcohol, carbonated drinks, chocolate and caffeine).
 - Avoid highly acidic foods like citrus, tomato products, onions.
 - Avoid high amounts of fatty or greasy foods.



Jan Warrick, and Colby, Gary & Georgia Marshall

- Remain upright for 1-2 hours after eating.
- Eat small, frequent meals (e.g., 3 meals plus 3 snacks daily).

- * Slow stomach emptying due to gastroparesis.
 - Medication prescribed by physician (e.g., Reglan, E-Myacin, Domperidone or Zelnorm)
 - Gastric pacemaker (Enterra therapy; www.medtronic.com/neuro/enterra).

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group members. Even if you only meet a select number of times per year, it's helpful to keep in contact with members during the times apart. Newsletters, e-mails, even telephone calls to check in can make all the difference in keeping your members connected and keeping you up-to-date on the latest issues and complications. It can also help you prepare materials for an upcoming meeting."

"Know Your Group": Is your support group made up of individuals living with scleroderma, caregivers, or individuals with other health concerns? Getting to know each member of the group, and their reasons for attending, can help you prepare meetings that address the needs of everyone—and not just one part of the group. Sometimes having group members fill out a questionnaire, or even talk about their own concerns is helpful."



Donna Stone (right) with chapter mates Maria Rivelli & Liz Orem-Bedel (center)

"Act As A Resource": As a support group leader, I cannot expect to have all the answers to a puzzling disease like scleroderma. What I do have, however, is time and the motivation to provide members with as many resources as possible. Listening to group members and learning about community and state-sponsored services that could help your mem-

bers can often make all the difference in the management of their symptoms."

"Encourage Personal (and Public) Advocacy": One of the lessons I've learned over the years as a mentor to so many is to encourage individuals to become their own advocate both for themselves and for the scleroderma community.

While education and awareness about scleroderma has significantly grown over the years and more individuals are aware of the disease, scleroderma patients and their families should not assume a passive approach to their health and medical care.

Teaching support group members and their caregivers and families on how to be an advocate for their health is something that will help them better manage their disease." []

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Nutritionist Lori S. Brizee MS, RD, LD, CSP speaks at Bend Support Group

* Poor nutrient absorption in small intestine due to slow movement of food resulting in bacterial overgrowth.

—Antibiotics prescribed by your physician.

—Promotility medications may be prescribed by your physician.

—Regular intake of "probiotics" (yogurt, kefir) may help prevent bacterial overgrowth.

—Nutrients of special concern: Vitamin B12, Vitamin D, Calcium, Folic Acid.

* Liquid multi-vitamin-supplement

* Liquid vitamin D supplement

* Liquid calcium supplement

* Diarrhea:

—Probiotics may help.

—Soluble fiber (in bananas, apples, oats) may help.

—Soluble fiber supplement (e.g., Benefiber or Metamucil) may help.

—Drink plenty of fluids to avoid dehydration. Half-strength orange juice is similar to Gatorade but has far more nutrients.

* Constipation:

—Increase fluid (no amount of laxatives or fiber will help without increased fluid). 64 ounces or more per day, unless physician has said to limit fluids.

—Increase fiber; whole grain breads, cereals, pastas, flax seed, nuts, fresh fruits and vegetables (try making

smoothies with whole fruit + juice + ground flax seed and/or nuts + ice in blender).

* Calcium:

—Requires about 1200 mg/day, more if you are on steroids. Talk with your physician if you have kidney issues before you start increasing calcium intake.

—Supplements: Oscal and Tums are excellent choices.

* Vitamin D:

—Requires about 1000-2000 IU/day, more if you are vitamin D deficient. Talk with your physician if you have kidney or liver issues. []