



SCLERODERMA  
FOUNDATION  
OREGON CHAPTER

July 2009

Volume 1, No. 6

# *Oregon Angels*

**City of Portland declares July 11, 2009 Scleroderma Awareness Day !**

## **Chapter's largest fundraiser and awareness event, Stepping Out to Cure Scleroderma walk, set for July 11**

The Oregon chapter's 4th Annual *Stepping Out to Cure Scleroderma* benefit walk is scheduled for Sat., July 11, 2009 at The Multnomah Art Center, 7688 SW Capitol Hwy., in Portland.

The event – the chapter's largest fundraising and awareness project to date – will include celebrities, entertainment, food, and family activities, in addition to the 2.8

mile-walk (shorter loop also available) which begins promptly at 11 am.

On-site registration (starting at 10am), check-in, and the walk all begin at The Multnomah Art Center. Walkers will stroll through the picturesque streets of Multnomah Village before entering lovely Gabriel Park.

Awards will be given for individual and team categories. Walk participants 14 and older pay a registration of \$20 (\$25 day of walk) and are encouraged to recruit fundraising sponsors to support their walk. A T-shirt will be provided to every paid registrant.

The Family Fun 2.8-Mile benefit walk helps to increase public awareness and raise funds for the many people in our area and across the country living with scleroderma.

Please register online at <http://www.firstgiving.com/scleroderma-oregon>

*Stepping Out* walkers will be warmly welcomed by Blaze the Trail Cat, official mascot for the NBA Portland Trail Blazers.

Blaze is expected to meet and greet walkers, help with the warm-up stretches, and even lead the walkers through the streets and into Gabriel Park! Blaze will be more than happy to take photos and sign paw-graphs.

**(continued on page 2)**



**Blaze will be there . . .**



**. . . and Fox 12's Debra Gil !**

(continued from page 1)

## Stepping Out to Cure Scleroderma walk, set for Saturday, July 11

Also joining *Stepping Out* is Portland television KPTV Fox 12's Debra Gil, who has graciously agreed to be the VIP Media representative for the 4th annual event. Debra Gil is the morning anchor and reporter for Fox 12 News. Gil will meet and greet the assembled walkers, as well as offer some public words of welcome just prior to the 11am start. A Fox 12 News crew is expected to cover it all!

On top of all that, July 11, 2009 has been officially proclaimed "Scleroderma Awareness Day" in Portland, Oregon by Mayor Sam Adams.

The proclamation reads, in part, "The

Oregon Chapter of the National Scleroderma Foundation has tirelessly served the interests of the state's residents living with Scleroderma and the related health-care community for more than twenty years of special events, educational series, and all-important continuing support groups."

When you register online, you have the opportunity to create your own web page. This makes it easy to share with friends and family about the event, and how they can support your efforts. To date, at least 21 web pages have been created! Please see more about creating your web page at <http://www.firstgiving.com/scleroderma-oregon>

Sponsors for the event include Portland Old Boys Breakfast Group, DiversiForm, Old Spaghetti Factory, Rose's Restaurants, Vitamin Shop, 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.

Additional information about walking tips, directions to the event and much more can be found at <http://www.scleroderma.org/chapter/oregon/pdf/2009/SclerodermaWalkBrochure09.pdf>



**Oregon Scleroderma Awareness team helped to inform and educate the public** on the set of Portland KATU Channel 2's "AM Northwest" live morning program. Chapter member Gaye Moye Jacobs (left), Support Group Leader Donna Stone, and Dr. Lauren H. Kim MD exchanged news and views with host Dave Anderson on June 29 during national awareness month. (Fay Maushard photo)



**Oregon Chapter Officers for 2009-2010** — Oregon chapter board members in May elected four officers for the current one-year term. The officers are Secretary Lawrence Maushard (left), President Liz Orem-Bedel, Vice-President Richard Bates, and Treasurer Janine Wong.

(continued from page 4)

## **Diagnosis of Systemic Sclerosis** by Lauren H. Kim MD

dysmotility, sclerodactyly and telangiectasia) mild changes in the fingers may be the only change, while for patients with diffuse scleroderma disease, the skin thickening may progress up the arm, often involving the trunk.

It is at this early stage of the skin change that one would like to see the correct diagnosis made to initiate early monitoring for possible internal organ involvement as well as to embark on the correct treatment.

With many of the gastrointestinal symptoms, it could be difficult to come up with the diagnosis of scleroderma without the hallmark skin changes since some of these symptoms are common in the general population.

Scleroderma has many gastric manifestations with involvement from the mouth to the anus: many patients develop difficulty swallowing; most develop GERD; some develop slowing of the gut in the small intestine causing the bad

bacteria in the gut to overgrow, manifesting as abdominal pain, bloating, diarrhea alternating with constipation (which in some patients can be severe enough to cause mild forms of gut obstruction requiring hospitalization); rectal incontinence is a problem for some patients as well. If a patient presents with more than a few of these symptoms, the diagnosis of scleroderma should be entertained.

One of the most important reasons for making an early diagnosis of scleroderma is so the patient can be monitored for early signs and symptoms of major internal organ involvement such as kidney disease and/or lung disease which can be life threatening.

With early recognition of these problems, one may be able to avoid kidney failure and/or permanent lung damage. Kidney and aggressive inflammatory lung damage occur more commonly in patients with diffuse skin disease; therefore, physicians caring for patients with rapidly progressive skin disease must be aware of the risks of these complications. The diagnosis of

scleroderma is more often missed in patients with limited skin disease because the symptoms can be so mild. The danger to missing the diagnosis in this group is that after about 8 to 10 years of disease, one's risk of another type of lung disease called pulmonary hypertension increases dramatically.

This is another disease where early detection may be important because with the discovery of many new drugs to treat this disease, physicians may be able to slow the progression, while if it is discovered in the very late stage, one to five year survival becomes dramatically low.

Scleroderma can be a challenging disease to diagnose because it is a rare disease. It is a disease not commonly seen by non-rheumatologists, but by creating awareness of the early signs and symptoms of it, early referrals to knowledgeable rheumatologists may result in improved care and quality of life for scleroderma patients. []

# SCLERODERMA FOUNDATION OREGON CHAPTER

P.O. Box 19296

Portland, Oregon 97280-0296

503-245-4588

orchapter@scleroderma.org

www.scleroderma.org/  
chapter/oregon



## SCLERODERMA FOUNDATION

SUPPORT · EDUCATION · RESEARCH

OREGON CHAPTER



**Plant Sale Soars for 12th Straight Season! — The annual May campaign earned more than \$1,000. These volunteers and others maintain our longest running fundraising and awareness event.**

**Diagnosis of Systemic Sclerosis . . .** by **Lauren H. Kim M.D.**, a rheumatologist practicing in the Portland area, 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.

Systemic Sclerosis (scleroderma) is an autoimmune disease whose name comes from the Greek word “scleros” — meaning thickened, hardened skin. Although the skin change is the hallmark of the disease, there are diverse manifestations of the disease, which may make it difficult for clinicians to correctly make the diagnosis of scleroderma.

***The most important factor in making the diagnosis of scleroderma is that a clinician must have some knowledge of the disease to consider it as a potential diagnosis.*** This is one of the important aspects of increasing awareness about the disease, not only for patients but also for all types of clinicians since patients come in contact with physicians from all fields.

It only takes that one physician to recognize the signs and symptoms to correctly embark on the road to the correct diagnosis.

One of the most common first manifestations of scleroderma is Raynaud’s phenomenon in which a person’s finger(s) and/or parts of one’s hand become white, reddish and purplish upon exposure to cold and/or stress. It can precede all other symptoms of scleroderma by as little as weeks to months or as long as decades.

Raynaud’s phenomenon can also occur alone with a benign natural history and no underlying autoimmune problem (common among young adult females).

If a person has Raynaud’s phenomenon and there is a family history of autoimmune disease such as rheumatoid arthritis, lupus or scleroderma, a physician may consider a referral to a rheumatologist to look for other signs and symptoms such as a positive ANA (antinuclear antibody) test or abnormal blood vessel changes around the nail beds which may be early signs of a possible underlying autoimmune disease such as lupus or scleroderma.

Other symptoms such as skin thickening and gastroesophageal reflux disease (GERD) can present around the same time.

In some patients, the development of skin thickening is a gradual process, with some patients noticing that the fingers have become fatter with time and their rings no longer fit. In others, it presents as diffuse painful puffiness of the fingers that are often misdiagnosed as rheumatoid arthritis.

For others, it occurs very rapidly resulting in contractures of the fingers due to tightness of the skin and damage to the underlying joints.

For patients with limited scleroderma (which used to be known as CREST syndrome—calcinosis, raynaud, esophageal

**(continued on page 3)**