

REACHING OUT



FALL 2009

SCLERODERMA FOUNDATION GREATER CHICAGO CHAPTER
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2009 HAS BEEN AN EXTRAORDINARY YEAR OF REACHING OUT



Photo: Christina Noel

Dear Friends of the Scleroderma Foundation,

It is with overwhelming gratitude that we write to *thank you* for all you have given to support our cause in the past year. It is amazing to me that so many people afflicted with this disease and their friends and families continue to strive to make the most of their lives and enrich the lives of others.

2009 has been an extraordinary year of reaching out. We have added new events, with a walk in Germantown Wisconsin, and a brand new event, "Cooking up a Cure" which drew over 200 people in October. We have sponsored two Patient Education Seminars and held our 4th Annual golf outing.

We have also seen our "Stepping Out to Cure" walks in Highland Park and Indiana grow in numbers and we held our 4th annual "Partners for a Cure" walk in Lake Geneva, WI. We have to thank many volunteers, who raised dollars for us with their third party events, all of them fun and inventive.



We have also participated in the national advocacy campaign, and have to thank all of the volunteers who visited their congressional and senate representatives and traveled to Washington on behalf of the Scleroderma Foundation. We have added two new Support Groups, and in 2010 will have a presence on Facebook and Twitter. We have even been seen on billboards around Chicago!

As we close out 2009, we have added four new Board of Trustee members to our local chapter board. Their commitment to our cause will only continue to strengthen our chapter and help us to help our patients. We will pursue new and exciting opportunities for fund-raising, awareness, patient support, and public education as we begin 2010.

For those of you who could not attend the events this year, or might wish to contribute further during this holiday season, we would ask that you please consider a gift to the Scleroderma Foundation, Greater Chicago Chapter. Your donation is truly appreciated.

We thank you for your continued support and wish you the most joyous of holiday seasons. See you in 2010!

Sincerely,

Ann Peterson
Executive Director, Greater Chicago Chapter

All Scleroderma informational brochures can be downloaded at www.scleroderma.org, click on "education and resources" and scroll down to brochure downloads.



MY LIFE WITH SCLERODERMA

By Kelly Kohls



It was just under a year since I had gotten married to my high school sweetheart and love of my life, 22 years old and a newlywed so happy, young and healthy. I would have never imagined what was about to unfold within the next several years of my life.

It was March 2003 and I started having pain in my hands and feet. Sometimes the pain in my feet was so excruciating that I couldn't even walk.

I had made several visits to my then Primary Care Physician with my concerns. At the time he took a full blood panel and minor tests along with an exam and his conclusion with no compassion what so ever, was nothing ...I was simply making it all up. Trying to plead with a doctor to convince them that you know something is wrong just didn't seem right to me, I needed to move on. After several more painful weeks had passed my husband had gotten a suggestion from his wonderfully caring employer for me to make an appointment with her family doctor who she trusted and was confident would be able to help me.

I visited the suggested doctor who I still see today as my primary physician, she was wonderful. Right off the bat she was almost certain what was wrong and referred me to a rheumatologist in the area. Dr. Kurt Oelke is who I met with, and he has been with me through it all since the first day of my diagnosis. I could not have asked more a more caring and compassionate doctor.

At the time I was diagnosed with Rheumatoid Arthritis due to the horrible pain I had been having in my joints. I honestly don't think it hit this 23 year old what that really meant. I knew it was serious but I figured we'll control it with medication and it will be no big deal.

Things were going ok. I was given several different medications, pills, at home injections and steroids but nothing seem to really truly make me feel better. About a year later I then started developing skin tightening and Raynaud's disease. Raynaud's disease is a condition resulting in a particular series of discolorations of the fingers and/or the toes after exposure to changes in temperature or emotional events. Skin discoloration occurs because an abnormal spasm of the blood vessels causes a diminished blood supply to the local tissues. This can be a painful condition that can also lead to

various skin problems due to the amount of time there is diminished blood flow in the extremities.

It was then at 24 years old I was diagnosed with Scleroderma. I had never heard of this... no one I knew had. I immediately started researching the disease, but as much knowledge as I could muster, I still don't think the seriousness of the disease had set into my young mind. My mom knew different, she was devastated that her "baby" was sick with this disease and she couldn't change it. She never let me go it alone. She was there every step of the way—every appointment, every test, scan, and injection. She, besides my husband, was my biggest support system through everything. My mother, my best friend, suddenly passed away of a cerebral aneurysm at the age of 51 a year and a half later, and I deal with the grief of her loss and getting through this with out her everyday.

Shortly after she had passed my methotrexate injections had been working well. I was feeling good despite the little changes I saw. The tightening on my hands and face, the increased acid reflux disease and increased Raynaud's disease when I went out in the bitter Wisconsin cold. The important thing was though, I was stable.

In November 2007 like any normal, married 27 year old women, I too had hopes and dreams of having a family and becoming a mommy. After much careful discussion with all my specialists we decided since the Scleroderma had been stable it was ok for me to discontinue my medication for one year to try to conceive.

Ecstatic and eager but with caution and uncertainty we proceeded with our journey to become parents!!

Several months passed and we hadn't any luck and by this time my body was starting to change again. I had an extreme lack of energy, shortness of breath, hair loss, chills, weight loss, insomnia and disturbing restless legs. Completely heartbroken, we decided it was time to give up on babies for now and try to get me better. After much testing we concluded that Scleroderma had affected my ability to produce enough red blood cells vital to my health. I was extremely anemic with Anemia from chronic disease. My iron levels and red blood cell counts had dropped to dangerous levels and it was imperative that we get them up, I started getting four-hour IV Iron Infusions in February 2009, and in May 2009 I started receiving sporadic blood transfusions. With out the infusions my blood counts could be fatal; I have been going in for them about every 4-6 weeks and have been slowly feeling better.

Unfortunately anemia is not the only thing I have endured since that time. My skin has changed rapidly... my fingers started to bend and cripple more, and the pain that comes along with it sometimes seems to be unbearable. My arms are also not able to extend fully like they used to. The tightening, as well as some hyper

pigmentation, has affected my face, neck, elbows, chest, back, legs and feet. The physical changes have been very emotional. Watching myself change from this disease sometimes makes me feel like a shadow of what I once was.

During a recent routine CT Lung scan I was told Scleroderma has also now developed in my lungs and I am in the early stages of Lung Disease.

It has been very physical as well as emotionally exhausting for my wonderful, supportive husband, Mike and I, and although there is no cure for Scleroderma, I am currently on the best medications that there is to offer. Even though sometimes it's tough, I stay as active as I can with normal daily tasks and working a full time job everyday. I have been lucky enough to recently become a patient at Northwestern University Hospital where Rheumatologists practice and research for people like me all day, every day!

Scleroderma, or systemic sclerosis, is a chronic connective tissue disease classified as one of the autoimmune rheumatic disease, and it affects an estimated 300,000 people in the United States. It is a devastating disease that affects the skin, joints and internal organs.

Never in my life plan did I ever think at the age of 29 I would start to lose my independence, my ability to put my own socks and shoes on, bend over to pick something up, hold things in my hand, get things out of the high cupboard, the embarrassment of dropping something on the floor at the store when I am alone, spend time outside, sit on the floor, and have a family of my own.

As of right now, there is no cure for Scleroderma, but doctors are researching hard everyday to find a cure for this debilitating disease that affects so many of us but just isn't talked about enough. Through my story I hope to raise your awareness of the disease, and hope that you can make a difference in the quality of life for me and so many others like me who need your help.

Kelly Kohls was one of our top fundraisers and contributors at our Germantown walk this year.

WELCOME NEW BOARD MEMBERS!

Cleetus Friedman, *City Provisions Catering & Events*;
Anna Hockett, *eflex group.com*; Darren Steele, *DVPS Inc.*;
and Joe Werner, *Pepsico, Tropicana Division*

2010 NATIONAL CONFERENCE HEADS TO BOSTON

Mark your calendars! The Scleroderma Foundation recently released the dates for its upcoming 2010 National Conference: July 30th-August 1st, 2010 at the Sheraton Boston Hotel located in downtown Boston! Discounted hotel rooms are already being set aside at the Sheraton for conference attendees and you can start making reservations within the "Scleroderma Foundation" room block now. Further information regarding conference registration and other details will be announced in upcoming E-letters as well as on the Foundation's web site.

ADVOCACY PROGRAM CONTINUES TO BUILD MOMENTUM

On July 30, Senator Kirsten Gillibrand (D-NY) introduced Scleroderma-specific legislation in the U.S. Senate. S. 1545, the "Scleroderma Research and Awareness Act" is a companion bill to H.R. 2408, the "Scleroderma Research and Awareness Act," which is being considered in the U.S. House of Representatives. The text included in both bills is the same. Each bill calls for significant increases in Scleroderma research funding at the National Institutes of Health (NIH) and for significant increases in funding for public awareness of Scleroderma by the Centers for Disease Control and Prevention (CDC).

Having two pieces of Scleroderma-specific legislation in the U.S. Congress is a significant step forward in the Foundation's effort to get Scleroderma-specific legislation passed in the U.S. Congress for the first time ever. Within a seven-day period, H.R. 2408 picked up ten congressional co-sponsors, which brings the official number of co-sponsors to 41.

The Foundation's Advocacy Program could not be more pleased with the progress it has made in 2009 in its ongoing effort to increase funding for Scleroderma research and increase public awareness of the disease.

HELP PASS THE "SCLERODERMA RESEARCH AND AWARENESS ACT"

On May 14th, Rep. Lois Capps (D-CA) and Rep. Vern Ehlers (R-MI) introduced a landmark bill aimed at expanding federal research and awareness programs on scleroderma. H.R. 2408, the "Scleroderma Research and Awareness Act" is the first bill ever introduced in the United States Congress focused exclusively on Scleroderma. You can help get this important legislation passed by contacting your representative and asking him/her to co-sponsor the bill. If you do not know who your representative is, please visit www.congress.org/congressorg/home. After finding your representative, advocates are encouraged to use their representatives web form found on their web site to send their letter. You may also fax your representative. That number is also on their web site. PLEASE DO NOT SEND LETTERS VIA REGULAR MAIL.

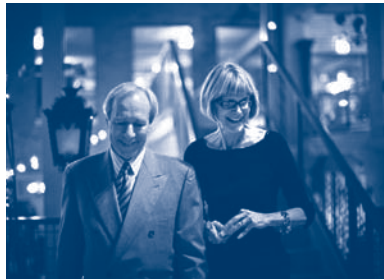
For further information about the two bills and about the Advocacy Program, please visit the Foundation's Advocacy Web page at: <http://www.scleroderma.org/advocacy/advohome.shtm>.

COOKING UP A CURE

CELEBRITY CHEF EVENT

Our first **COOKING UP A CURE WAS A GREAT SUCCESS.** We wish to thank our Presenting Sponsor, *Roy and Paula May*, and all of our participating restaurants and vendors.

- August Hill Winery
- Birchwood Kitchen
- Bittersweet Cafe
- Bleeding Heart Bakery
- Carnivale
- Carol's Cookies
- Carousel Linens
- City Provisions
- Catering and Events
- Crop to Cup
- David Burke's Prime House
- Death's Door Spirits
- Floriolo Bakery
- Halls Rental
- Heaven on Seven/
The Purple Pig
- Ina's
- Nice Cream
- Smoque
- Swim Cafe
- T-Bones Steak House
- Two Brothers /
Windy City Distributing
- Uncommon Ground
- Veeraway
- Viaand



Christina Noël
photography

We would also like to thank Christina Noël for the beautiful photography for this event.
christina@christinanoelphotography.us

2009

A GREAT YEAR FULL OF FUN EVENTS FOR SCLERODERMA PATIENTS AND FRIENDS



Black Women's Expo



Highland Park Walk



Highland Park Walk



Teeing Up "Fore" Scleroderma

SUPPORT GROUPS

Support Groups provide a forum to share feelings, concerns, information, as well as a place to offer peer support and encouragement. Solicitations or research projects are not conducted at support group meetings. This schedule is subject to change. Before attending a group for the first time, please call to verify date and time. Groups are free of charge and open to everyone.



Indiana Walk



Germantown Walk



Lake Geneva Walk



Northwestern Patient Education Day



Northwestern Patient Education Day



Spring Education Conference, U of C

OAK PARK, ILLINOIS

Scleroderma Support Group of Western Suburbs 10 a.m. the third Saturday of each month. Our meetings are held at West Suburban Hospital, One Erie Court. Please check at the information desk for room location.

There is FREE parking in the garage. At our meetings, we give and receive support from one another. Contact: Monica Geary, P 708.386.7198 E westernsuburbsil@scleroderma.org. Support Group Leaders: Pauline Geary P 708.362.0350 E psgeary@yahoo.com. and Natalie Nemeth

TWO NEW SUPPORT GROUPS HAVE FORMED IN 2009!

ILLIOPOLIS, ILLINOIS

Illinois Library, 6th and Mary St.
Support Group Leader: Debbie Deaton,
P 217.720.2327

E sclerodermasupport@comcast.net

CHICAGO, ILLINOIS

Next meeting: Saturday Dec. 12, 10:30 a.m.
40 E 9th St. #304

Support Group Leader: Seth Reagen
P 847.420.5208 E sethnr@gmail.com

HIGHWOOD, ILLINOIS

Phone/Email Support: Shirl Halpern,
P 847.432.3198

E starkohalpern@comcast.com

KANKAKEE, ILLINOIS

Kankakee County Support Group
10:00 a.m. to 12:00 p.m.
the last Sat. of each month.

Riverside Medical Center
350 N. Wall St.
Support Group Leader: Lisa Somers
P 815.933.0993 E prinprin76@sbcglobal.net

PERU, ILLINOIS

Illinois Valley Support Group
Phone or e-mail support only.
Support Group Leader: Lynn Schmidt
P 815-539-5897
E illinoisvalley@scleroderma.org

GOSHEN, INDIANA

Northern Indiana Support Group/Northern Indiana Disability Advocacy Network, Inc. (NI-DAN)
Saturdays, 10:00 a.m.–12:00 p.m.

Goshen Public Library (574.533.9531)
601 S. 5th St., Room A/B

Support Group Leader: Janine Capon
P 574.536.8274 E northernindiana@scleroderma.org

LAKE GENEVA, WISCONSIN

10 a.m.–12 p.m. first Saturday of each month
Aurora Health Center, 136 East Geneva Square
Family members are welcome!

Support Group Leader: Shari Lundberg
P 262.245.6212 E lakegenewawi@scleroderma.org

MILWAUKEE, WISCONSIN

Southeastern Wisconsin Support Group.
No formal meetings. Telephone support with group members. Share your concerns or just looking for information we hope we can support you in your struggle with Scleroderma.

Support Group Leader: Sandra Walter
P 262.338.0980 E sandi_wb@mac.com.

GREEN BAY, WISCONSIN

Northeastern Wisconsin Support Group.
Meetings 2:00-3:00 p.m.

Harmony Cafe, 1660 West Mason Street
Support Group Leader: Jackie Means
P 920.469.7623 E sclerodermawi@yahoo.com

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REACHING OUT

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Executive Director

Judi Riley
Art Director

For information, to contribute articles and suggestions, or to be added to our mailing list, please contact Ann Peterson at: apeterson@scleroderma.org

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Scleroderma Foundation
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www.scleroderma.org

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WHAT IS SCLERODERMA?

Scleroderma is a chronic, often progressive, autoimmune disease like Rheumatoid Arthritis, Lupus, and Multiple Sclerosis – in which the body's immune system attacks its own tissues. The disease, which literally means "hard skin," can cause thickening and tightening of the skin, as well as serious damage to internal organs including the lungs, heart, kidneys, esophagus, and gastrointestinal tract. For some individuals, Scleroderma is a nuisance – for others it is a life-threatening disease.

An estimated 300,000 persons in the United States have Scleroderma; Approximately four times more women than men develop the disease. The exact cause or causes of Scleroderma are unknown, and although medications can sometimes help, there is no cure yet.



RETURN SERVICE REQUESTED
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