

## Tell Me More

### WHAT KIND OF SCLERODERMA DO I HAVE?

A question and answer session with:

Nicole Fett, M.D.

Department of Dermatology, Perelman Center for Advanced Medicine

South Pavilion, 1st Floor, 3400 Civic Center Boulevard, Philadelphia, PA 19104



Nicole Fett is an Assistant Professor of Dermatology at the University of Pennsylvania and a staff dermatologist at the VA Hospital in Philadelphia. Dr. Fett completed her combined training in Internal Medicine and Dermatology at the University of Wisconsin Hospital and Clinics, and is board certified in both specialties. Dr. Fett has a specialty clinic in autoimmune skin diseases at the University of Pennsylvania.

#### 1. How many forms of scleroderma exist?

There are four distinct subsets of scleroderma: localized scleroderma, limited cutaneous systemic sclerosis, diffuse cutaneous systemic sclerosis, and systemic sclerosis sine scleroderma. In addition, all four types can occur in the setting of an additional autoimmune disease (such as systemic lupus erythematosus or rheumatoid arthritis) and the combination of the two is referred to as an overlap syndrome.

#### 2. What does systemic sclerosis mean? Is it the same as saying scleroderma?

Scleroderma is a broad, inexact term for all four subsets of disease (morphea, limited cutaneous systemic sclerosis, diffuse cutaneous systemic sclerosis, and systemic sclerosis sine scleroderma). Systemic sclerosis was adopted as a more exact term for those patients that do not have localized scleroderma.

#### 3. What is localized scleroderma?

Localized scleroderma, also referred to as morphea, affects the skin and sometimes the tissues directly underneath the involved skin (such as the muscle, tendon, bone, and brain). The vast majority of patients with localized scleroderma do not have Raynaud's phenomenon (spasm of the blood vessels in their fingers leading to color changes of red, white and blue), do not have changes in the capillaries along their nails, do not have sclerodactyly (thickening of the skin of the fingers) and do not have involvement of their internal organs. Localized scleroderma can present in a linear form that affects the limbs or the forehead, a plaque form that manifests as circles of skin thickening, a generalized form (defined as involvement of two or more body areas), a deep form (affecting underlying tissue), and a mixed form (involving two or more of the above classifications). Patients with localized scleroderma may feel tired and achy, and may have positive auto-antibodies such as anti-nuclear antibodies (ANA). Localized scleroderma does not decrease a patient's lifespan.

#### 4. What is limited cutaneous systemic sclerosis?

Limited cutaneous systemic sclerosis, previously referred to as CREST syndrome (see question #12), is diagnosed in patients who have Raynaud's phenomenon (usually this has been present for 5 to 10 years before diagnosis), dilation in the capillaries along their nails, and thickening of the skin of their fingers, hands, and forearms. Patients with limited cutaneous systemic sclerosis may also notice thickening of the skin around their mouths, and may develop telangiectasias (small dilated blood vessels). Patients with limited cutaneous systemic sclerosis may also develop ulcerations on their fingers from severe blood vessel spasm and resultant decreased oxygen.

#### 5. Does limited cutaneous systemic sclerosis only affect the skin?

Limited cutaneous systemic sclerosis can affect the internal organs. The lungs can form fibrosis (scar) much like the skin. This is called pulmonary fibrosis or interstitial lung disease (ILD). Patients with limited cutaneous systemic sclerosis can also have involvement of their pulmonary artery. The pulmonary artery is a blood vessel that brings blood from the right ventricle (the large chamber on the right side of the heart) to the lungs. Once the blood is in the lungs it picks up oxygen and is then delivered to the left side of the heart, which pumps it to the rest of the body. Involvement of the pulmonary artery can lead to increased blood pressure in that vessel, also referred to as pulmonary artery hypertension (PAH). PAH makes it harder for the right heart to pump blood to the lungs, causing a back up of blood in the liver and legs and less available oxygenated blood for the rest of the body. This can result in heart failure. Patients with limited cutaneous systemic sclerosis should have pulmonary function testing and transthoracic echocardiograms yearly to monitor for these complications. Limited cutaneous systemic sclerosis can also affect the esophagus, making it difficult to swallow, or allowing acid from the stomach to enter the esophagus causing "heart burn" and tissue damage. The sclerosis can also affect the remainder of the gastrointestinal tract, leading to bloating, constipation, and malabsorption.

#### 6. What is diffuse cutaneous systemic sclerosis?

Diffuse cutaneous systemic sclerosis is diagnosed in patients who have Raynaud's phenomenon (usually this has been present for only a short period of time prior to diagnosis), dilation in the capillaries along their nails, and thickening of the skin of their fingers, hands,

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# THE PRESIDENT'S *Bit*

It is a pleasure to welcome another dedicated board member to our Foundation!

## Katayun Jaffari, Esquire

Katayun is a partner of Saul Ewing LLP, a 260 attorney law firm. Her expertise as a corporate lawyer in the Business Department seems a logical end result of her preparation first at Temple where she earned a BBA in Finance and Legal Studies and an MBA with a concentration in International Business and Human Resources. In 1995, she graduated from The George Washington University Law Center with her Juris Doctor.

Of the many accomplishments Katayun has achieved, the most significant for us is her devotion to pro bono and public interest issues. She brings to our chapter a wealth of experience from other worthy not for profit organizations. The Scleroderma Foundation Delaware Valley Chapter is the fortunate recipient of her time and knowledge due to the unfortunate burden of her mother's diagnosis with scleroderma. As is the case with most of our board, we relate to the cause from a very personal perspective. She is supportive of her mother and has now extended that support to our Foundation with her guidance as a board member.

Please join me in welcoming Katayun Jaffari to the Board of the Scleroderma Foundation Delaware Valley Chapter.

To succeed in our Mission, we need not only the leadership provided by our committed office staff but also participation from a Board of Directors willing and able to guide our Foundation. The following highlight the responsibilities typical of our Board:

- Engages in ongoing planning activities as necessary to determine the mission of the organization and its strategic direction

- Evaluates the success of the organization's services toward achieving the mission.
- Promotes awareness of SFDV i.e. speaking at functions, news, radio, TV or at gatherings one on one.
- Approves policies for the effective, efficient, and cost-effective operation of the organization.
- Approves the organization's budget and assesses the organization's financial performance in relation to the budget
- Actively participates in the fundraising process through members' financial support and active seeking of the support of others.
- Hires, set the compensation for, and annually evaluate the performance of the Executive Director.
- Ensures that an internal review of the organization's compliance with known existing legal, regulatory, and financial reporting requirements is conducted annually and that a summary of the results of the review is provided to the entire board.
- Attend either via phone conference or in person, at least 75% of all board meetings. There are 5 scheduled board meetings each year.

Please contact us at 1-866-675-5545 or 856-779-7225 for any questions you may have and please consider an opportunity to be of service on our Board.

*Respectfully submitted: Susan Pierce, President Delaware Valley Scleroderma Foundation*



## Executive Director's Desk

### SCLERODERMA AWARENESS MONTH

The month of June is recognized nationally as Scleroderma Awareness Month. The SFDV has been active in obtaining Proclamations from our State and local legislators. We thank...

Governor Chris Christie of New Jersey  
Governor Ed Rendell of Pennsylvania  
Governor Jack Markell of Delaware  
Mayor Michael A. Nutter of Philadelphia  
Mayor George Dempsey of Manasquan, NJ  
Mayor James Baker of Wilmington, Delaware

...Who have all made official proclamations in their respective States and communities. The goal of these documents is to raise the level of awareness of scleroderma in both local and State government which will hopefully lead to more support in both the private and public sectors and ultimately to research that will find new treatments and eventually a cure for this misunderstood disease.

Please keep in mind that it doesn't have to be June to promote scleroderma awareness. We can all participate by the little things we do. Don't be shy! Wear your walk T-shirt when you are out shopping, Facebook your friends, write a letter to the editor, leave an information card in your doctor's office – let your family, friends, and co-workers know that we need their support to find a cure. Awareness is a year round commitment, but June is a great time to start.

Chris



## Gift

The Scleroderma Foundation Delaware Valley Chapter received a generous gift of \$45,000 from the Estate of Joan Lindeman. Joan was a thoughtful, intelligent person who suffered from several physical ailments. As she had no heirs, she researched and chose the charities to inherit her estate very carefully. It is a great compliment to our organization that we were chosen to receive this gift in the company of institutions like the Children's Hospital of Philadelphia. We are mindful of her generosity in carrying out our mission to educate, promote awareness, and support research for those suffering with scleroderma.

## SFDV Office

Scleroderma Foundation  
Delaware Valley Chapter  
385 Kings Highway North  
Cherry Professional Building  
Cherry Hill, NJ 08034  
856-779-7225  
866-675-5545  
DVchapter@scleroderma.org  
www.scleroderma.org/chapter/delaware\_valley



**Disclaimer:** The Scleroderma Foundation in no way endorses any drugs or treatments reported in this newsletter or at SFDV sponsored meetings. Information is provided as a resource to be used with discretion. Because the manifestations and severity of scleroderma vary among individuals, personalized medical management is essential. Therefore, it is strongly recommended that all drugs and treatments be discussed with one's physician to assure proper evaluation and treatment.



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forearms, and above their elbows and knees. Patients with diffuse cutaneous systemic sclerosis can have problems with thickening of the skin around their mouths, telangiectasias, interstitial lung disease, pulmonary artery hypertension and gastrointestinal involvement similar to patients with limited cutaneous systemic sclerosis. Patients with diffuse cutaneous systemic sclerosis tend to have more skin and tendon fibrosis, and are at higher risk of involvement of the blood vessels in the kidneys. Patients with diffuse cutaneous systemic sclerosis should carefully monitor their blood pressure. Blood pressure elevation may be a sign of kidney involvement, also referred to as scleroderma renal crisis.

## 7. What is sine systemic sclerosis?

Systemic sclerosis sine scleroderma is a rare subtype of scleroderma that results in internal organ fibrosis, but no skin fibrosis. Patients with systemic sclerosis sine scleroderma almost uniformly have Raynaud's phenomenon and dilation of their nailfold capillaries. They can also go on to form gastrointestinal fibrosis, pulmonary fibrosis, and pulmonary artery hypertension.

## 8. What are the main differences between the four types of scleroderma?

To summarize, the main differences between the four groups is as follows.

**P**atients with morphea do not have Raynaud's phenomenon, sclerodactyly, or internal organ involvement.

**P**atients with limited cutaneous systemic sclerosis do not have involvement of the skin above their elbows and knees (with the exception of the face), and have a slower disease onset compared to patients with diffuse cutaneous systemic sclerosis.

**P**atients with diffuse systemic cutaneous sclerosis have an explosive onset with severe Raynaud's phenomenon and finger ulceration and are at increased risk of kidney involvement compared to patients with limited cutaneous systemic sclerosis.

**S**ystemic sclerosis sine scleroderma affects the internal organs and blood vessels, but does not cause skin fibrosis.

## 9. Why is it important to identify the form of scleroderma a patient has? Does it affect treatment or predict the progression of the disease?

Identifying the form of scleroderma a patient has is important because it affects our screening for complications, treatment decision making, and gives us information about prognosis. Patients with localized scleroderma are not at risk for life threatening internal complications. This knowledge helps us balance the risks of medications against the risk of the disease morbidity, and decreases unnecessary screening. Patients with limited cutaneous systemic sclerosis, diffuse cutaneous systemic sclerosis, and systemic sclerosis sine scleroderma are at risk of interstitial lung disease and pulmonary artery hypertension. Therefore, these patients should have screening for these complications via pulmonary function tests with diffusion capacity

testing and transthoracic echocardiograms yearly. Patients with diffuse cutaneous systemic sclerosis are at increased risk of kidney involvement and should regularly monitor their blood pressure. Patients with limited cutaneous systemic sclerosis tend to have a slowly progressive disease course, whereas patients with diffuse cutaneous systemic sclerosis tend to have a rapidly progressive disease course.

## 10. Can one form of scleroderma turn into another form, i.e. can localized scleroderma turn into systemic scleroderma, or can limited scleroderma turn into diffuse scleroderma?

Although nothing is ever absolute, localized scleroderma, limited cutaneous systemic sclerosis and diffuse cutaneous systemic sclerosis are thought of as three distinct disease states that do not turn into one another. This is reflected by the distinct clinical presentations and tempo of each disease as well as their individual gene signatures and autoantibody production.

## 11. What does CREST mean? Is it different than other forms of scleroderma?

CREST is an acronym for Calcinosis, Raynaud's phenomenon, Esophageal dysmotility, Sclerodactyly, and Telangiectasia that was used in the past to usually denote limited cutaneous systemic sclerosis. The term CREST has fallen out of favor, as not all patients with limited cutaneous systemic sclerosis have all manifestations listed in the acronym. The preferred nomenclature is now limited cutaneous systemic sclerosis.

## 12. Are there certain lab tests that can be done to tell the difference between the types of scleroderma?

The physical exam remains our best tool for discerning the differences between subtypes of scleroderma. The majority of patients have auto-antibodies (proteins from the immune system accidentally targeted against the patient) in their blood, however, the absence of these auto-antibodies does not rule out the disease. These include anti-nuclear antibodies (ANA), anti-centromere antibodies, and anti-Scl 70 (also known as anti-topoisomerase) antibodies. The most common seen in all subtypes of scleroderma is anti-nuclear antibodies (ANA). Patients with limited cutaneous systemic sclerosis are more likely than patients with other types of scleroderma to have anti-centromere antibodies and are at an increased risk of isolated pulmonary artery hypertension. Patients with diffuse cutaneous systemic sclerosis are more likely to have anti-Scl 70 antibodies and have an increased risk of pulmonary fibrosis. Researchers continue to search for auto-antibodies that are sensitive (i.e. almost 100% of patients with a certain subtype have the auto-antibody) and specific (i.e. only patients with that subtype have the particular auto-antibody) for each sub-type of scleroderma.

**We would like to thank Dr. Fett for sharing her time and expertise and helping us become better informed about scleroderma.**

## Donation to Research

Thanks to the generosity of our members and scleroderma supporters the SFDV was able to make a contribution of \$25,000 in 2009 to the National Scleroderma Foundation Research Grant Funding Program. A total of \$1,050,000.00 was awarded to 7 worthy researchers this year through this program. A Peer Review Committee guided by N.I.H. protocol and criteria evaluated 31 grant applications to determine the strongest proposals. The hope of finding a cause and cure for scleroderma is only possible through continued scientific research. Carol Feghali-Bostwick, P.H.D., researcher and Vice Chair of the Foundation's Board of Directors states, "Our understanding of scleroderma has increased dramatically over the past decade, thanks to the continued support of the Scleroderma Foundation's Research Grant Funding Program."

Our chapter mission mandates that we stimulate and support research and we are grateful to all whose contributions make this possible.

Thank you.

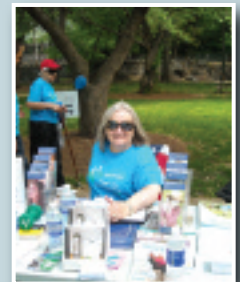
# Inaugural Delaware 5K Run and Walk – May 8, 2010

The scleroderma community in Delaware came together on May 8, 2010, for the Inaugural “Stepping Out To Cure Scleroderma” 5K Run and Walk in beautiful Brandywine Park in Wilmington, Delaware. Wayne Kursh and Jon Clifton from Races 2 Run did a great job creating an official 5K. Nearly 100 walkers and runners participated in what will surely become an annual spring event.

### Teams With Most Walkers:

1st Place	Waffy’s Walkers	27
2nd Place	Team Sharon	10
3rd Place	Team Personti	7

We are especially thankful to all the volunteers who came out to help make this new event a success – your spirit and enthusiasm made the day memorable for everyone.





## Feet First! Patient Education Conference on Podiatric Care and Rehabilitation March 23, 2010

Have you ever thought about how the health of your feet affects the rest of your body? On March 23, 2010, **Nicholas Romansky, D.P.M. of Healthmark Foot and Ankle in Media and Pottstown, PA**, and **Michael Groh, PT of Leading Edge Physical Therapy in Media, PA**, spoke at our Patient Educational Conference in Newtown Square, PA, at the Bryn Mawr Health Center. Our attendees enjoyed a light lunch and the informative seminar from our podiatry specialists. We all learned more about how our feet play a role in our overall health and well being, as well as ways to deal with foot problems and the value of rehabilitation in maintaining that well being. For those who were unable to attend, this conference was videotaped and is available on loan through our office.

**Thank you** to Dr. Romansky and Michael Groh for taking the time to support scleroderma.

### SCLERODERMA AWARENESS NIGHT WITH THE PHILLIES



**Have you been thinking of going to a ball game this summer?**

**Please join us at Citizens Bank Park on Tuesday, July 27**

**when the Phillies host the Arizona Diamondbacks at 7:05 p.m.**

Seating will be located in the Terrace Deck (Sections 424-425) at \$26 per ticket.

**Net proceeds from tickets sold through this event will benefit the Scleroderma Foundation of Delaware Valley.**

To order your tickets go to [www.phillies.com/sfdv](http://www.phillies.com/sfdv) or call the sales office at 215-463-5000 and tell them you are with the SFDV group.

**Please place your orders by June 27.**

**Tickets are subject to availability.**

We hope to see you at Citizens Bank Park on July 27!



On October 7, 2009, Susan Pierce, Board president, and Christine Gaydos, Executive Director, from the Scleroderma Foundation Delaware Valley Chapter spent the day in Washington, DC, meeting with lawmakers in an effort to obtain support for S1545 and HR2408 – the Scleroderma Research and Awareness Act. The day was quite successful with Senator Frank Lautenberg (pictured above) and Representative Chris Smith co-sponsoring their respective bills. To date 9 Senators and 94 House Representatives have signed on including Senator Robert Menendez of New Jersey, Representatives Joe Sestak, Charles Dent and Christopher Carney from Pennsylvania, and Representatives Steven Rothman and Frank LoBiondo from New Jersey.

**BUT, we need more support in Washington. Please don't let these bills die in Congress. This is a great way to get involved and help make a difference. If you haven't done so already contact your State Representative or Senator and tell him you would like to tell your story. We can help you find out who your representative is, help you make an appointment or write a letter, and accompany you on your visit. Contact the office at 866-675-5545 or email at [dvchapter@scleroderma.org](mailto:dvchapter@scleroderma.org) for more information.**

# 2010 National Patient Education Conference in Boston

"Where Revolutionary Ideas Begin"

## Conference Registration

Conference workshops are scheduled for Saturday, July 31st and Sunday, August 1st, but all participants are invited to attend a welcome reception, including light hors d'oeuvres, on Friday, July 30, from 6 to 8 p.m.

Register by phone at 1-800-722-4673 or contact the Scleroderma Foundation at [scleroderma.org](http://scleroderma.org).

### Registration Fees:

Now through July 7: \$185 for members and \$235 for non-members.

After July 7: \$235 for members and \$285 for non-members.

Meal Functions Only (no workshops): \$115.

Registration for a child 12 years of age & under: \$20.

### Conference Registration Fee includes:

All Conference activities and scheduled meal functions, as follows:

**Friday:** reception (light hors d'oeuvres)

**Saturday:** breakfast, lunch, and Awards Dinner

**Sunday:** brunch

### Meal Functions Only Fee Includes:

**Friday:** reception (light hors d'oeuvres, dinner on your own)

**Saturday:** breakfast, lunch, and Awards Banquet

**Sunday:** brunch

## Office News

If you've called the office and heard a new voice it is that of Nancy Aichholzer, our new office assistant. Actually Nancy started back in October 2009. You might have met her at the Philadelphia Walk where she experienced her first scleroderma walk.

Nancy grew up and attended school in South Jersey and lives in Mount Laurel. She was previously employed as an administrative assistant and worked at Cendant Mortgage for 10 years. Currently Nancy covers the office part time on Thursdays and Fridays.

Having Nancy on board has allowed our office to expand and tackle our expanded calendar with confidence. We are happy to have her with us. Welcome Nancy.

## For all Music Lovers!

### Oliver Creak CD for sale \$5.00

Claire Farra was a loving mother and grandmother. She was also a gifted musician. Claire and her three close friends formed the group "Oliver Creak" and performed all over the Philadelphia area as well as numerous radio appearances. They produced the CD "When's the Day" which features all original songs. Sadly, Claire lost her battle with scleroderma in June 2009. Oliver Creak has donated their CD featuring Claire. All proceeds will go to support the Scleroderma Foundation Delaware Valley Chapter in Claire's memory. You can sample two of the music tracks through our website [www.scleroderma.org/chapter/delaware\\_valley](http://www.scleroderma.org/chapter/delaware_valley). Copies of this CD can be obtained by calling the office at 866-675-5545.

2010 National Gold Sponsor



# Scleroderma Foundation Delaware Valley Chapter Support Groups

385 Kings Highway North, Cherry Professional Building, Cherry Hill, NJ 08034

856-779-7225 • 866-675-5545 • Fax 856-779-7266 • Email: DVchapter@scleroderma.org • Website: www.scleroderma.org

## Support Group Meeting Locations

### Cherry Hill, NJ (Burl-Cam)

SFDV office, 856-779-7225, DVchapter@scleroderma.org.  
2nd Thursday of every other month starting in January at 1:30 pm  
385 Kings Highway North, Cherry Professional Building  
Cherry Hill, NJ

### Monmouth, NJ

Support Group Leader: Marsha Niederman, 732-276-5807,  
mjniederman@optonline.net  
2nd Saturday of the month at 10:00 am (except Jan, Feb, July & Aug)  
Contact support group leader for meeting location

### Warren, New Jersey (Watchung Hills)

Support Group Co-leader: Ellen Waldstein, 908-647-7266,  
ellw@optonline.net  
Support Group Co-leader: Chris Frascella, 908-604-6054  
2nd Tuesday of the month at 2:00 pm, quarterly – January 6, March 3,  
June 8 at 12:30 (contact support group leader for meeting location),  
October 12  
Trinity United Church, 118 King George Road, Warren, NJ

### Woodbury, NJ

Support Group Leader: Mary Nuzzo, 856-582-6456,  
marynuzzo@msn.com  
1st Tuesday of the month, quarterly at 7:00 pm - March 2, June 2,  
September 2, December 6  
Underwood Memorial Hospital, Dining Room B, 1st Floor  
238 S Evergreen Avenue  
Woodbury, NJ

### Doylestown, PA

Support Group Leader: Mary Gocek, 215-942-9477  
4th Monday of the month at 6:30 pm  
Doylestown Hospital  
1st floor – North Wing – Conference Room B  
595 West State Street, Doylestown, PA  
Contact support group leader prior to attending meeting

### Langhorne, PA (Bucks County)

Support Group Leader: Ilene Nusblatt, 215-321-1670,  
inusblatt@comcast.net  
Wednesdays at 1:30 pm – March 24, June 23, September 22,  
November 24 -2010  
Frankford Hospital - Bucks County, Conference Room C – ground floor  
380 N. Oxford Valley Road, Langhorne, PA

### Philadelphia, PA

Support Group Leader: Joyce Roby-Washington, 215-474-0259,  
joycerw757@msn.com  
2nd Wednesday of the month at 1:00 pm  
Starbucks at Target, 4000 Monument Road @ City Line Avenue  
Philadelphia, PA

### Norristown, PA

Support Group Leader: Joanne Cipollini, 610-644-1582  
or 610-270-2703, jcipollini@mont-hosp.com  
Support Group Co-leader: Andrea, 215-483-2260  
4th Wednesday of the month at 6:30 pm  
Montgomery Hospital Medical Center  
1301 Powell Street, Norristown, PA

### Reading, PA

Support Group Leader: Dawn Batzel, 610-287-1445.,  
happy81070@verizon.net  
Meets every other month on Saturdays at 10:00 am – January 9, March  
13, May 8, July 10, September 11, November 13  
Reading Pediatrics office, 40 Berkshire Court, Wyomissing, PA

### Williamsport, PA

Support Group Leader: Jayne Young, 570-323-4228,  
weyclu@sunlink.net  
Support Group Co-leader: Gayle Bullock, 570-398-0551  
1st Wednesday of the month at 1:00 pm (except July & August)  
Life Center in the Lycoming Mall, 300 Lycoming Mall Cir #3021  
Muncy, PA

### Wyalusing, PA

Support Group Leader: Janet Baker, 570-746-1278,  
cadreaming@frontiernet.net  
1st Wednesday of the month at 2:00 pm  
Wyalusing Public Library, 202 Church Street, Wyalusing, PA  
Contact support group leader prior to attending meeting

### York, PA

Support Group Leader: Kathleen Gaskell-Blankenship, 717-428-1464,  
karlkathleen@earthlink.net  
Meets quarterly on Wednesdays at 7:00 pm – June 16  
Elmwood Mansion Conference Center  
400 Elmwood Blvd. (Corner of S. Belmont St & Elmwood Blvd)  
York, PA



**E-mail Support Group**

We have started an e-mail support group for those patients and families that are not close to one of our existing support groups or those who would like to participate in addition to attending a support group. There is a weekly topic of discussion by email and everyone is free to comment or ask a question at any time. You can participate as little or as much as you like. If you are interested in being part of an email support group, please contact the office at 856-779-7225 or via e-mail at cferara@scleroderma.org.

## Support Group Leaders Needed

We are always looking to expand our support groups into new areas. Please contact our office if you are interested in becoming a Support Group Leader.

### Delaware

Newark/Wilmington Area  
Southern DE Area

### New Jersey

Cape May Area  
New Brunswick Area  
Toms River Area

### Pennsylvania

Carlisle/Harrisburg Area  
Doylestown Area  
Lehigh Valley Area  
Delaware County Area

# The Pursuit



NEWSLETTER OF THE SCLERODERMA FOUNDATION  
DELAWARE VALLEY CHAPTER  
385 KINGS HIGHWAY NORTH  
CHERRY PROFESSIONAL BUILDING  
CHERRY HILL, NJ 08034

NON-PROFIT ORG.  
U.S. POSTAGE  
**PAID**  
Permit No. 1940  
BELLMAWR, N.J.

## PLANNING AHEAD

### June 6, 2010

10th Annual "Stepping Out to Cure Scleroderma" Walk  
Manasquan, NJ

### June 14, 2010

Bruce MacCutcheon & Marilyn Lacy Memorial Golf Classic

### July 27, 2010

Phillies Game – Scleroderma Awareness Night

### July 30 to August 1, 2010

National Conference in Boston, MA

### August 7, 2010

Golf Outing  
Ramblewood Country Club, Mount Laurel, NJ

### August 14, 2010

6th Annual "Stepping Out to Cure Scleroderma" Walk, York, PA

### October 10, 2010

21st Annual "Stepping Out to Cure Scleroderma" Walk,  
Philadelphia, PA

### September 10, 2010

9th Annual "Teri's Run" – Downingtown, PA

### October 23, 2010

Joint Educational Patient Conference in New Brunswick, NJ

Check our website at [scleroderma.org/chapter/Delaware\\_valley](http://scleroderma.org/chapter/Delaware_valley) for news and information. Check out our Facebook page for frequent postings [www.facebook.com/pages/Delaware-Valley-Chapter-for-Scleroderma-Foundation/179200360685](http://www.facebook.com/pages/Delaware-Valley-Chapter-for-Scleroderma-Foundation/179200360685)

### MISSION STATEMENT



To help patients and their families cope with Scleroderma through mutual support programs, peer counseling, physician referrals and educational information.



To promote public awareness and education through patient and health professional seminars, literature and publicity campaigns.



To stimulate and support research to improve treatment and ultimately find the cause and cure of Scleroderma and related diseases.

