

The Pursuit *Support Education Research*

JUNE IS SCLERODERMA AWARENESS MONTH

NEWSLETTER OF THE SCLERODERMA FOUNDATION ~ DELAWARE VALLEY CHAPTER

April 2011

Department of Defense Grant to Dr. Elizabeth Blankenhorn at Drexel University School of Medicine

You may have noted in the recent issue of the Scleroderma Foundation Voice that three scleroderma researchers were awarded grants from the United States Department of Defense. Dr. Elizabeth Blankenhorn, a geneticist at Drexel University School of Medicine, is part of a consortium of researchers including Dr. Carol Artlett at Drexel University College of Medicine and Dr. Mike Whitfield at Dartmouth Medical School, who received these awards. In a recent conversation Dr. Blankenhorn described her study and hopes of getting significant insight into the disease process resulting in what we know as scleroderma.

Dr. Blankenhorn will be studying a population of mice that show very similar symptoms of human scleroderma such as skin thickening, autoimmunity, and the deposit of collagen-like material outside of cells. These mice were originally bred in England and brought to the United States by a colleague studying fibrosis. The first step of the study will be to identify which gene is responsible for causing the genetic mutation that causes the scleroderma type



Skin from normal mouse



Thickened skin from affected mouse (Note the change in density)

symptoms. With that knowledge potential parallels could be made to genetic studies

being done in humans. Part two of the study will be looking at the excess production of TGF-beta, a protein associated with the cell growth and expressed in both the mice and humans.

Why are studies like this important to understanding scleroderma in humans? Studying mice that are genetically programmed to show the same symptoms every time they are bred enables us to study the disease process much earlier. Knowing that the mice will develop the disease every time (because of the genetic abnormality) gives the advantage of gathering data from the day they are born. At this point in time scleroderma in humans is not able to be diagnosed until well after symptoms appear – a huge problem in helping people obtain an early diagnosis and early treatment when possible.

In 2009 Dr. Blankenhorn was the recipient of a Scleroderma Foundation research grant, the Mark Flapan award. Her study, “Genes That Regulate the Scleroderma Trait in Mice” was the cornerstone to being awarded this current grant from the Department of Defense. The Scleroderma Foundation awards grants totaling approximately \$1,000,000 a year to basic researchers like Dr. Blankenhorn who seek to uncover the mechanism(s) that cause scleroderma. The SFDV along with all the other chapters in the United States is active in raising money that goes directly to financing these research grants. We are grateful to all those who support the SFDV and its mission of education, awareness, and research.

Submitted by Christine Gaydos

“SFDV Receives Grant from the George W. Rentschler Foundation”

In January 2011, our chapter was generously awarded a \$3,000 grant from the George W. Rentschler Foundation of Philadelphia, PA. The grant is for continued funding of researchers whose proposals are rated highest by a Research Review Board operating under the jurisdiction of the National Scleroderma Foundation.

We sincerely thank the George W. Rentschler Foundation for their generous gift and continued support of research to improve treatments and ultimately find the cause and cure of scleroderma and related diseases.



Focus on research

As you know, funding research to find the cause and cure for scleroderma remains at the very heart of our chapter’s mission. Through the generosity of the scleroderma community in 2010 the SFDV was able to contribute \$30,000 to the National Scleroderma Foundation’s research grant program. Twenty-seven grant applications were received, reviewed, and selected according to merit by the Foundation’s Peer Review Committee for 2011. The Peer Review process, guided by National Institutes of Health (NIH) protocol and criteria, ensures Foundation dollars are put towards the strongest research proposals. This year, six researchers - five established and one new investigator – submitted proposals that received fundable scores. They are as follows:

- Maria Trojanowska, Ph.D., Boston University School of Medicine
- Shu Wu, M.D., University of Miami
- Alisa Koch, M.D., University of Michigan
- Galina Bogatkevich, M.D., Ph.D., Medical University of South Carolina
- Monique Hinchcliff, M.D., Northwestern University Feinberg School of Medicine
- Xiaodong Zhou, M.D., University of Texas – Houston

Congratulations to the recipients of the Scleroderma Foundation research grants.



Thank You Wendy!!

The SFDV would like to recognize the talents and efforts of Wendy Faggart in providing the design and layout that goes into our annual walk brochures. This year Wendy also worked on our 2nd Annual Delaware 5k Run/Walk postcards and designed our new scleroderma information bookmarks. Wendy who lives in the York, PA, area also coordinates the York Walk held every August and participates in the York Support Group. We are grateful to her for all her help – Thank you Wendy.

Bridges to Hope

The 2011 Scleroderma Foundation National Patient Education Conference will be held from July 8 to July 10, 2011, in San Francisco, CA, at the Hilton San Francisco Union Square. This year's conference will feature workshop topics including scleroderma treatment, disease management, and coping techniques. Those attending will have the opportunity to listen to and meet scleroderma researchers and clinicians from across the country, as well as meet and network with other scleroderma patients and supporters. To register or for more information about this year's conference contact Lindsey Bergman at lbergman@scleroderma.org or call 1-800-722-4673.



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 tissue.

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. Scleroderma occurs three to four times more often in women than men.

Symptoms of scleroderma vary from mild to severe. For some, it can be a life threatening disease. For most people with Scleroderma, the disease has a serious impact on daily life and although medications can sometimes help, there is no cure yet.

for more information contact the



Crocheting for Scleroderma

Erika Tanczos is passionate about crocheting – so passionate that it led her to open a web-store at etsy.com/shop/knellybean where she sells her handmade accessories. Erika is also passionate about scleroderma awareness. Her mother received the diagnosis of scleroderma a year ago. Not only does Erika now donate a portion of her sales to the Scleroderma Foundation, but she makes sure every customer receives an

information card or brochure making them aware of scleroderma. In her own words, "I just want people to know what it is, it's irritating that most people do not know the word scleroderma."

Erika is now working on a granny square afghan and is looking for 8" granny square donations to complete this project. The proceeds from the sale of this afghan would be donated to the Scleroderma Foundation. If you are a crocheter and can donate a few squares to complete this project please mail them to P.O. Box 57, Tatamy, PA, 18085. For any questions you can contact Erika through her website, etsy.com/shop/knellybean or the SFDV office at 866-675-5545.

We invite you to visit Erika's web-store to view her lovely handmade neck scarves and accessories and we applaud Erika and her entrepreneurial spirit for the support she provides her mother and the scleroderma community.

A Patient's Perspective

Each week the email support group shares interesting stories with one another. The group is a wonderful source of support for the fifty members. One patient describes living with scleroderma and how the disease has affected her.

I was 9 years old and perfectly normal before the scleroderma hit me. Even though I was diagnosed at an early age, I had no real treatment. Basically the linear scleroderma was left to ravage me. My parents didn't know what to do. They took me to a doctor who basically used me as a guinea pig with experimental medicines, etc. I hated him. My parents really did not check into things and NEVER questioned the doctors. They were of the generation that thought doctors are God. As a child I used to question the doctors and try to stand up for myself and my mom would be so embarrassed by me. As an adult I was finally free to advocate for myself and that is when I found my orthopedic specialist and surrounded myself with doctors who I respect and who I know respect me.

Dr Jimenez told me a few years ago that if I had come to Thomas Jefferson University, the doctors probably could have helped slow the disease and wasting down. Last year, Dr. Jimenez asked me to be at a conference as an example of linear scleroderma in a child that is left untreated. I also have the coup de sabre - the mark of the sword across my face. Basically, I look like 2 bodies in one. My left side is thin, rigid and my right side is fleshy. I look like I weigh 105 lbs on my

left and 140 on the right and it is very difficult to buy clothes. My case is extreme. My toes on my left foot are completely curled under and it is like walking on bone. My ankle is fixed – permanently – in to a dropped position and my left leg is tiny. I look like I have polio. As a teen I sometimes used a wheelchair, but usually I limped because I hated using a wheelchair. (I'm stubborn). I walked on this from the time I was 14 – 25 years old. Then I was in Europe and found an orthopedic specialist who invented these boots that enable me to walk without touching my toes on the ground. The boots compensate for the fixed ankle and my other foot issues. It is AMAZING!!! I can now walk without a limp and without pain (usually). At this point I am unable to stand on my bare foot and I HAVE to wear the boot to walk or stand. I don't think this will happen to any of you since there are more treatments and physical therapy that is available today. Remember, I was left totally untreated. I often think, if only I had physical therapy, maybe my leg would not have wasted away or my ankle would not be fixed, etc. Take charge and question everything. And only use doctors that you feel respect you and LISTEN to you!!

Betsy O'Donohue is 52 years old and this is her personal story of living with scleroderma for the past 42 years. If you have an interesting story that you would like to share, please contact the SFDV office.

JOINT CHAPTER EDUCATIONAL FORUM – OCTOBER 23, 2010

Dr. Sean Studer and Ms. Jan Gnall were guest speakers at the Joint Chapter Educational Forum sponsored by the Delaware Valley and Tri-State chapters of the Scleroderma Foundation held at Robert Wood Johnson University Hospital on October 23, 2010. This forum has become a yearly event bringing together the scleroderma communities in both North and South New Jersey. Approximately 50 participants attended this year's forum.



**Jan Gnall, guest speaker,
Jay Peak, TriState Chapter, and
Chris Gaydos, Delaware Valley Chapter**

Dr. Studer presented an "Update on the Management of Lung Disease in Scleroderma: A Focus on Pulmonary Hypertension." He is currently the Medical Director of Lung Transplantation and Director of Pulmonary Hypertension at Beth Israel Medical Center in Newark, NJ, and has trained and worked at several medical centers active in scleroderma treatment including the University of Pittsburgh in Pennsylvania, Johns Hopkins Hospital in Maryland, and Mount Sinai Medical Center in New York City. Dr. Studer discussed the affects of scleroderma on the lungs and heart including pulmonary fibrosis and pulmonary hypertension. In addition to

providing an excellent presentation and answering questions from the room, he graciously made himself available to individuals with questions after his talk.



**Dr. Sean Studer speaking on
Lung Disease in Scleroderma**

Ms. Jan Gnall, author of the workbook, "Be Your Best Advocate," presented a talk entitled, "Be Your Best Advocate: Living With Scleroderma." As a scleroderma patient herself and an active Assistant Support Group Leader in Hackensack, NJ, she shared ways in which scleroderma patients can be more proactive in their medical care including ways to share information with their physicians and therapists and ways to improve their own medical records. Ms. Gnall was also gracious in remaining "overtime" to address questions from individuals.

The Tri-State Chapter also honored Mrs. Heidi Fox, with an award of appreciation for her ongoing support and dedication to their chapter and the Scleroderma Foundation.

We would like to thank United Therapeutics for their assistance in arranging Dr. Studer's presentation, as well as Actelion, the 2010 National Gold Sponsor of the Scleroderma Foundation.

Both talks are available on sclerodermavideo.com or on DVD through the SFDV office.

TERI'S RUN RAISES \$10,500 FOR SCLERODERMA RESEARCH!!!

Downingtown, PA....500 Runners and Walkers in Chester County, PA, participated in the 9th Annual Teri's Run on September 9, 2010. Every year the family and friends of Teri Valocchi hold this event in her memory and the memory of those who have lost their battle with scleroderma. Teri's Run features a 5K run, walk, and a kid's run – a real family event. The course starts and stops on Green Street and features a flat, fast course. Over 25 local businesses sponsored this great day which also featured refreshments, raffle prizes, and awards. The Downingtown Police deserve many thanks for their help in organizing the registration site and their help with road closings.

Save the date – September 9, 2011, for the 10th Annual Teri's Run.

The SFDV is very thankful for the Teri's Run donation of \$10,500, which goes directly to research. Each year the National Scleroderma Foundation awards approximately \$1,000,000 in grant money to researchers seeking the causes and cure of scleroderma. For more information go to scleroderma.org and click Research.



Seeking bloggers and newsletter contributors! There are health benefits to writing out your thoughts. Contact Chris at the SFDV office if you are interested.

Reduce Stress by Journaling (Healthywoman.org)

by Pamela M. Peeke, MD, MPH

When life's challenges seem overwhelming, women often find that talking about their stress helps them put it in perspective. However, there's another great way to maintain control of your thoughts and decision making throughout each day: Journaling.



I don't mean writing long and detailed stories of your life experiences. Journaling is the simple act of regularly jotting down your life events and feelings on paper-or even at your lap top, desk top, or typewriter. Your journal can help you refine your daily living skills. It gives you the opportunity to reflect on the experiences/events you've recorded.

You can use journaling to help you deal with stressors you don't feel comfortable sharing with others. Stress psychologists have shown that journaling enhances immune function and can alter the course of chronic conditions such as rheumatoid arthritis and asthma. Here are some tips to get you started:

Subject? Focus on current stressors. Writing about stress helps you step back and consider your options more clearly.

Technique? To improve health and decrease stress, journal

entries should include two things: First, write what happened -- the facts about the objective experience. Second, write your feelings about what happened, what you feel and why you feel it.

Content? Don't hold back! Write continually for about fifteen minutes with no censoring, until you feel you get it all out.

Tone? Don't worry. Just let it all hang out. Don't stress over the spelling and grammar. Let it flow and enjoy the process of communicating important feelings on paper.

When? Write whenever you want or feel you need to. If you have been keeping food diaries to track your eating, perhaps you can combine this with journaling.

How much? Try it for fifteen minutes a day, everyday.

Should you share? It is wise to keep your journal to yourself. If you write thinking you may share it, you may be tempted to write for that person. A journal is about you and your self-care.

Hate to write? Try talking into a tape recorder. It can be just as good, though perhaps less convenient.

How will I feel? Some feel a sense of relief; others feel depressed for a time after writing. This will go away, though, as you gain a better understanding of yourself, and your life.

Remember: Writing thoughts and feelings is not a replacement for professional therapy. If you think you might be depressed (if you're sad or overwhelmed feelings don't go away or they interfere with your daily functioning) or, if you are suffering from a trauma or other mental health problem, seek help from a licensed professional.

Journaling is a form of preventative maintenance. It's another tool in your stress resilience toolbox. So buy yourself a beautiful journal or create an electronic one, and get to writing!

Helpful Hints for Living with Scleroderma

Once a week members of the email support group share their thoughts on varying subjects. Some of their suggestions for making life easier for those suffering with scleroderma appear below:

For warmth:

www.wintersilks.com

instant heat packs

littlehottieswarmers.com

heating blanket

Hand Warmer to Help Ease Raynaud's
Quarterback's Secret Hand Warmer sells for \$21.50 plus shipping. For further information or to order the hand warmer (item 75086), visit www.duluthtrading.com or call 800-505-8888.



For hygiene:

Vaseline Sheer Infusion hand lotion – penetrates layers of skin

Cetaphil for sensitive skin

Biotene products for dry mouth

MedActive products for dry mouth . . . Contact medactive.com or 1-866-887-4867 for free samples.

Colgate Wisps (tiny one-use toothbrushes with a little dollop of toothpaste in the middle and the other end can be used to floss);

they are a lifesaver on days when my mouth won't open much or my hands and wrists are flaring up.
Nexcare waterproof bandages

Silipos gel pads

For comfort:

Wedge pillow for sleeping

Seat from Relax Your Back. It has a hole cut out for your spine.

For ease:

"As Seen on TV" battery operated jar opener and can openers

The grabber is also a helpful tool to use when picking things up off of the floor or reaching for things that are too high.

Have a 2nd vacuum upstairs to reduce heavy carrying loads

Toilet seat "riser" or "booster seat" – do not have to bend my knees much to sit and it has padded handles for getting up.

Shower chair – so worth the investment. Available with a back, not just the bench, and handles and attachments to hold things. Showering requires a lot less energy and there's no risk of slipping or falling.

The shower benches are also wonderful to just sit on the edge and then swing your legs into the tub.

Other suggestions:

Hyperbaric Oxygen Therapy Treatments

Chewing bubble gum and making bubbles to exercise mouth muscles.

SCLERODERMA FOUNDATION DELAWARE VALLEY CHAPTER SUPPORT GROUP CALENDAR

April

- 6 – Williamsport Support Group at 1:00 pm
- 9 – Monmouth Support Group at 10:00 am
- 13 – Philadelphia Support Group at 1:30 pm
- 25 – Doylestown Support Group at 6:30 pm
- 25 – North Delaware Support Group at 6:00 pm
- 27 – Norristown Support Group at 6:30 pm

May

- 4 – Williamsport Support Group at 1:00 pm
- 11 – Philadelphia Support Group at 1:30 pm
- 12 – Burl-Cam Support Group at 1:30 pm
- 14 – Monmouth Support Group at 10:00 am
- 14 – Reading Support Group at 10:00 am
- 15 – Camp Hill Support Group at 3:00 pm *New*
- 23 – Doylestown Support Group at 6:30 pm
- 23 – North Delaware Support Group at 6:00 pm
- 25 – Norristown Support Group at 6:30 pm

June

- 1 – Williamsport Support Group at 1:00 pm
- 1 – Bucks County Support Group at 7:00 pm
- 7 – Woodbury Support Group at 7:00 pm
- 7 – Watchung Hills Support Group luncheon
(contact support group leader for location)
- 8 – Philadelphia Support Group at 1:30 pm
- 11 – Monmouth Support Group at 10:00 am
- 12 – Camp Hill Support Group at 3:00 pm *New*
- 22 – Norristown Support Group at 6:30 pm
- 27 – Doylestown Support Group at 6:30 pm
- 27 – North Delaware Support Group at 6:00 pm

July

- 9 – Monmouth Support Group at 10:00 am
- 9 – Reading Support Group at 10:00 am
- 10 – Camp Hill Support Group at 3:00 pm *New*
- 13 – Philadelphia Support Group at 1:30 pm
- 14 – Burl-Cam Support Group at 1:30 pm
- 25 – Doylestown Support Group at 6:30 pm
- 25 – North Delaware Support Group at 6:00 pm
- 27 – Norristown Support Group at 6:30 pm

August

- 10 – Philadelphia Support Group at 1:30 pm
- 13 – Monmouth Support Group at 10:00 am
- 14 – Camp Hill Support Group at 3:00 pm *New*
- 22 – Doylestown Support Group at 6:30 pm
- 22 – North Delaware Support Group at 6:00 pm
- 24 – Norristown Support Group at 6:30 pm

September

- 6 – Woodbury Support Group at 7:00 pm
- 7 – Williamsport Support Group at 1:00 pm
- 7 – Bucks County Support Group at 7:00 pm
- 8 – Burl-Cam Support Group at 1:30 pm
- 10 – Monmouth Support Group at 10:00 am (different location)
- 10 – Reading Support Group at 10:00 am
- 14 – Philadelphia Support Group at 1:30 pm
- 26 – Doylestown Support Group at 6:30 pm
- 26 – North Delaware Support Group at 6:00 pm
- 28 – Norristown Support Group at 6:30 pm

October

- 5 – Williamsport Support Group at 1:00 pm
- 8 – Monmouth Support Group at 10:00 am
- 11 – Watchung Hills Support Group at 2:00 pm
- 12 – Philadelphia Support Group at 1:30 pm
- 24 – Doylestown Support Group at 6:30 pm
- 24 – North Delaware Support Group at 6:00 pm
- 27 – Norristown Support Group at 6:30 pm

November

- 2 – Williamsport Support Group at 1:00 pm
- 9 – Philadelphia Support Group at 1:30 pm
- 10 – Burl-Cam Support Group at 1:30 pm
- 12 – Monmouth Support Group at 10:00 am
- 12 – Reading Support Group at 10:00 am
- 23 – Norristown Support Group at 6:30 pm
- 28 – Doylestown Support Group at 6:30 pm
- 28 – North Delaware Support Group at 6:00 pm

December

- 6 – Woodbury Support Group at 7:00 pm
- 7 – Williamsport Support Group at 1:00 pm
- 7 – Bucks County Support Group at 7:00 pm
- 10 – Monmouth Support Group at 10:00 am
- 14 – Philadelphia Support Group at 1:30 pm
- 26 – Doylestown Support Group at 6:30 pm
- 26 – North Delaware Support Group at 6:00 pm
- 28 – Norristown Support Group at 6:30 pm

Support Group Meeting Locations

DELAWARE

Wilmington, Delaware (North Delaware)

Support Group Leader: Debra Wagner,
610-255-5768 or 610-864-6669,
scleroderma.desupport@comcast.net
4th Monday of every month at 6:00 pm
Kirkwood Library, 6000 Kirkwood Hwy
Wilmington, DE 19808-4817
302-995-7663

NEW JERSEY

Cherry Hill, New Jersey (Burl-Cam)

Support Group Leader: John Keegan, 856-767-4783, johnkeegan@comcast.net
2nd Thursday of every other month starting in January at 1:30 pm
385 Kings Highway North, Cherry Professional Building, Cherry Hill, NJ 08034
856-779-7225

Monmouth, New Jersey

Support Group Leader: Marsha Niederman, 732-276-5807, mjniiederman@optonline.net
2nd Saturday of the month at 10:00 am
Neptune Twp Public Library
(Sept meeting at another location)
2nd floor conference room
25 Neptune Blvd., Neptune, NJ 07753
732-775-8241

Warren, New Jersey (Watchung Hills)

Support Group Leader: Ellen Waldstein, 908-647-7266, ellw@optonline.net
Support Group Co-Leader: Chris Frascella, 908-604-6054, co-leader
Tuesday at 2:00 pm, quarterly - January 18, March 8, June 7 (luncheon meeting at another location), October 11
Trinity United Church
118 King George Road, Warren, NJ 07059
732-469-5044

Woodbury, New Jersey

Support Group Leader: Mary Nuzzo, 856-582-6456, marynuzz@msn.com
1st Tuesday of the month, quarterly at 7:00 pm - March 8, June 7, September 6, December 6
Underwood Memorial Hospital
Dining Room B, 1st Floor (December meeting)
Medical Arts Building (adjoining building) - Suite 14 (March, June & September meetings)
509 North Broad Street, Woodbury, NJ 08096
856-845-0100

Please contact support group leader prior to attending meeting.

PENNSYLVANIA

Camp Hill, Pennsylvania

Support Group Leader: Stacy Hunt, 717-609-3256, eclipselover2@aol.com
Sunday at 3:00 pm - May 15, June 12, July 10, August 14
Giant Foods Community Center
3301 East Trindle Road, Camp Hill, PA 17011
(717) 724-1166

Doylestown, Pennsylvania

Support Group Leader: Mary Gocek, 908-256-3408, marymuffin@gmail.com
4th Monday of each month at 6:30 pm
Doylestown Hospital
1st floor - North Wing - Conference Room B
595 West State Street, Doylestown, PA 18901
215-345-2200

Langhorne, Pennsylvania (Bucks County)

Support Group Leader: Ilene Nusblatt, 215-321-1670, inusblatt@comcast.net (June and December meetings)
Support Group Leader: Sharon Durham, 215-638-2771, icoachjoy@hotmail.com (March and September meetings)
First Wednesdays quarterly at 7:00 pm - March 2, June 1, September 7, December 7
Aria Health - Bucks County
Conference Room C - ground floor
380 N. Oxford Valley Road,
Langhorne, PA 19047
215-949-5000

Norristown, Pennsylvania

Support Group Leader: Andrea Balkiewicz, 610-495-7976, and1300@verizon.net
4th Wednesday of the month at 6:30 pm
Montgomery Hospital Cancer Center
1330 Powell Street, Suite 308,
Norristown, PA 19401
610-270-2000

Philadelphia, Pennsylvania

Support Group Leader: Joyce Roby-Washington, 215-474-0259 or 267-516-6987, joycerw757@msn.com
2nd Wednesday of the month at 1:30 pm
Presbyterian Medical Center, University of Pennsylvania Health System
39th and Market Streets,
Wright Saunders Building
Gardner Conference Room 128-C
Philadelphia, PA 19104
215-662-8000

Reading, Pennsylvania

Support Group Leader: Dawn Batzel, 610-287-1445, happy81070@verizon.net
2nd Saturday of every other month at 10:00 am - March 12, May 14, July 9, September 10, November 12
Reading Pediatrics office
40 Berkshire Court, Wyomissing, PA 19610
610-374-7400

Williamsport, Pennsylvania

Support Group Leader: Jayne Young, 570-323-4228, weyclu@sunlink.net
Gayle Bullock, 570-398-0551 (co-leader)
1st Wednesday of the month at 1:00 pm (except January, February, July & August)
Life Center in the Lycoming Mall
300 Lycoming Mall Cir #3021,
Muncy, PA 17756
570-546-6879

York, Pennsylvania

Support Group Leader: Kathleen Gaskell-Blankenship, 717-428-1464, karlkathleen@earthlink.net
Meets quarterly on Wednesdays at 7:00 pm - next date to be determined
Elmwood Mansion Conference Center
400 Elmwood Blvd. (Corner of S. Belmont St & Elmwood Blvd), York, PA 17402



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
Southern DE Area

New Jersey
Cape May Area
New Brunswick Area
Toms River Area

Pennsylvania
Lehigh Valley Area
Delaware County Area

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.

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

UPCOMING EVENTS

April 16 – 2nd Annual “Stepping Out to Cure Scleroderma”
5K Run & Walk, Wilmington, DE

May 7 – Educational Seminar TBD, Allentown, PA

June 5 – 11th Annual “Stepping Out to Cure Scleroderma”
Walk, Manasquan, NJ

June 13 – Bruce MacCutcheon & Marilyn Lacy Memorial
Golf Classic

July 8-10 – National Conference in San Francisco, CA

Aug. 13 – 7th Annual “Stepping Out to Cure Scleroderma”
Walk, York, PA




Sep. 9 – 10th Annual “Teri’s Run” – Downingtown, PA

Oct. 9 – 22nd Annual “Stepping Out to Cure Scleroderma”
Walk, Philadelphia, PA

Oct. 15 – Joint Educational Patient Conference, Somerville, NJ

Check our website at 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.

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.

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

