

The Pursuit

Support Education Research

NEWSLETTER OF THE SCLERODERMA FOUNDATION ~ DELAWARE VALLEY CHAPTER Winter 2014

Stepping Out to Cure Scleroderma Philadelphia Walk



We did it....we tackled all the forms, the date setting challenges, the parking issues, the permit and license filings, the gathering of donors and sponsors, and what were we left with - a fabulous time!

A beautiful day on October 5, 2014 hosted the 25th Annual Stepping Out to Cure Scleroderma Walk on the banks of the Schuylkill River on Kelly drive in Philadelphia. Along with all the devoted participants, this year we had the pleasure of having Dr. Nora Sandorfi, Associate Professor of Clinical Medicine Department at the Perelman School of Medicine at the University of Pennsylvania, and her daughter, as well as Sue Serio, Weather Anchor, Good Day Philadelphia and her daughter, in attendance. Dr. Sandorfi was gracious to cut the ribbon for the start of our walk and she received a plaque in appreciation for her years of serving our patient community, while Sue Serio assisted with calling the winners of our wonderful prizes and 50/50. As always, this walk remains our largest and most family-oriented event.

The countless volunteers pulled off yet another extraordinary walk complete with teal colored cupcakes to celebrate the walk's 25th anniversary. This quarter century event also saw the roll out of new technology in the acceptance of on-site credit card processing for SFDV!

We were also in the presence of a masterful balloon artist who formed every shape the kids and grownups alike requested of him. Along with the balloon artist, we had the privilege of having a team of face painters who did amazing drawings on kids and even grownups.

This year's top teams for **MOST WALKERS** include:

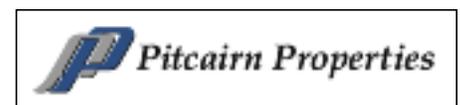
- 1st place Joey - 57 walkers
- 2nd place Bhagat - 53 walkers
- 3rd place Cimini - 45 walkers

The awards for **MOST MONEY RAISED** at last year's walk in 2013 include:

- 1st place Cimini - raised \$20,830
- 2nd place Bonnie's Cruisers - raised \$8,054
- 3rd place Rosie - raised \$6,580

As always, we are grateful to the Bhagat family for our team pictures. Visit our web site at www.sfdv.org to see all the pictures, select "Your Community", then "Photo Gallery" and select "2014 Philly Walk Photos".

We are looking to form a committee for the Philly walk in 2015 and would love to have you participate on this team. For further information about the committee, please call me at 856-779-7225 or email me at fsepahi@scleroderma.org.





Your Autoimmune Diagnosis Can Help Others!

Donate your plasma to help advance diagnostics and diagnostic research.

Plasma Services Group compensates our donors for their time and efforts.

Being a plasma donor not only helps to advance the diagnostic abilities of the medical community, but can also off-set healthcare costs associated with your diagnosis.



Please contact our Director of Donor Recruitment for more information:

Virginia Glass
Plasma Services Group
Email: vglass@plasmaservicesgroup.com
Office: (215) 355-1255 ext. 306



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Do you shop online at Amazon?
If so, use your Amazon profile and shop through <https://smile.amazon.com/>

– Amazon donates 0.5% of the price of your eligible Amazon Smile purchases to the charitable organization of your choice.

– Amazon Smile is the same Amazon you know – same products, same prices, and same service.

– Support SFDV by starting your shopping at smile.amazon.com. Once logged in search for Scleroderma Foundation of the Delaware Valley and then shop, shop, SHOP!

United Way Giving

Does your company participate in United Way giving?
If so, we will appreciate you contributing to SFDV.

If you use UWGPSNJ use **391722** to locate Scleroderma Foundation of the Delaware Valley (SFDV)
You may also locate us under UWSEPA **9415**.

We truly appreciate your contribution!



Forty Under Forty Award Ceremony Honors Jessica Jones

In attendance from left to right: William Cowan SFDV Board Member, Joan Forrer SFDV Board President, Jason Jones, Jessica Jones, Fee Sepahi SFDV Executive Director and Chris Gaydos SFDV Board Member. SFDV Board Members and staff gathered to celebrate the Burlington County Times Forty under Forty award ceremony honoring Jessica Jones for her efforts in raising funds for SFDV. Jessica and Jason, in the past two years have raised over \$20,000 in an effort to find a cure for scleroderma. Their team Bonnie's Cruisers not only participates in several walks, but they also hold a Chinese Auction in Mount Holly, NJ to raise even more funds and awareness.



Everything Will Be Alright *Submitted by Penny Nicholl*



“Everything will be alright!” Words Bob Nicholl used to comfort his family even during his own struggles. Bob was diagnosed with Scleroderma in 2003 after issues with his skin and hands. In 2010 when his breathing became labored, he was always exhausted, and had endured several emergency room visits. Dr. Ami Shah at Bay View Scleroderma Center accepted him for treatment and he was admitted to Johns Hopkins critical care unit. Bob

and his wife, Penny traveled from northern PA to Baltimore sometimes twice a week for appointments. Bob never gave up hope or trying to live life to the fullest. He continued to work and spend time with his family. Bob was a history buff remembering dates and names when no one else could. He enjoyed being in the “situation room with Wolf Blitzer via his recliner”, and loved traveling. Eventually relying on oxygen limited travel, but he participated in a pulmonary rehab program three days a week. He treasured time with his granddaughter Hannah, his children Dustin and Caitlin, and his family. Bob volunteered for every study that Dr. Shah recommended. He tolerated blood draws at every doctor visit so he could help others by allowing researchers to record his vitals and progression data – All in the hope of finding a cure. Bob loved life and approached each day with hope, faith, and a positive outlook. In June 2013, Bob was headed to his garden to plant some tomatoes when he lost his struggle to pulmonary hypertension, a complication of scleroderma. We are better

people because Bob was part of our lives. We continued to “pay it forward” in honor of Bob by participating in our first Stepping Out to Cure Scleroderma Walk in York, PA. Our team wore white socks with red stripes to honor Bob’s life, strength, courage, individuality, zest for life, and of course his crazy lack of fashion sense when it came to his socks! We miss Bob every day, but we see his beautiful blue eyes in his new grandson, Jace. Never give up hope and everything will be alright!



Pappy Bob Nicholl Family and friends

National Scleroderma Foundation Patient Conference Held in Anaheim, CA

The 2014 National Scleroderma Foundation Patient Conference was held in Anaheim, California just two blocks away from Disneyland! The event was packed with over eighty sessions and more than five hundred participants. Patients, chapter leaders and physicians alike were treated to great hospitality by the Southern California Chapter and the former San Diego Chapter, now part of the newly formed Southern California Chapter. The never ending venue of the Anaheim Marriott hotel and conference center was an ideal location for this magnificent gathering.

There were at least seventy-nine workshops offered by leading professors, researchers, scholars and physicians. Subjects covered ranged from

Scleroderma 101 to advocacy in Washington, DC. An update on Morphea and PAH and stem cell presentations from actual patients, were just a few of the many available sessions.

The keynote opening session was presented by Dr. Carol A. Feghali-Bostwick, Kitty Trask Holt Endowment Chair and Professor of Medicine in the Division of Rheumatology and Immunology at the Medical University of South Carolina.

The closing keynote was presented by Dr. Daniel E. Furst. Dr. Furst is the first Carl M. Pearson Professor of Medicine at the University of Southern California Medical Center. You can find both speeches on the National Scleroderma Foundation

youtube.com video page at: <https://www.youtube.com/channel/UCIH1E5RDegr0WRVISgo9Fw> or simply search for 2014 Scleroderma Foundation National Conference at www.youtube.com

The event along with being jam packed with valuable information and new research, offered a tremendous amount of networking and relationship building. Attendees ranged from Australia, India, China and many other lands.

The next conference will be held in Nashville, TN on July 17-19, 2015. Save the date and contact us if you have an interest in attending. We’d love to have a great SFDV showing at this event!

Stepping Out to Cure Scleroderma Allaire Walk

In the early summer on June 7, our 14th Annual Stepping Out to Cure Scleroderma Walk was held at Allaire State Park in Farmingdale, NJ. Just about 300 walkers wandered through the fields and Historic Allaire Village. They enjoyed walk t-shirts, refreshments, raffle prizes, a 50/50 drawing and meeting others connected to scleroderma. Over **\$30,000** was raised at the annual event. The walk was a success thanks to the generosity of scleroderma patients, family, and friends.



This year's top teams for **MOST WALKERS** include:

- 1st place Grandma Doris' Kids – 46 walkers
- 2nd place Snow White – 43 walkers
- 3rd place Joy's Mission Remission – 35 walkers

The awards for **MOST MONEY RAISED** at last year's walk in 2013 include:

- 1st place Bonnie's Cruisers – raised \$9,627
- 2nd place Bruce's Angels – raised \$5,935
- 3rd place Grandma Doris' Kids – raised \$4,070



We appreciate the support of our local businesses including **New Jersey Laboratories** who sponsored the walk for the second year and **Actelion Pharmaceuticals** who has sponsored each of our chapter's walks this year. **Silver Line Building** has sponsored our shore walk for the past four years and we appreciate their continued support. Thank you to our event donors including: Starbucks of Howell, NJ, Entenmanns Bakery Outlet of Cherry Hill, NJ, and Ocean Trophies of Lanoka Harbor, NJ. Thanks to Nancy Waltermire for this year's raffle prizes. Thank you to our wonderful volunteers who continue to give their time to the Foundation each and every year. We can always count on the volunteers! We look forward to seeing you again next June.



Stepping Out to Cure Scleroderma York Walk

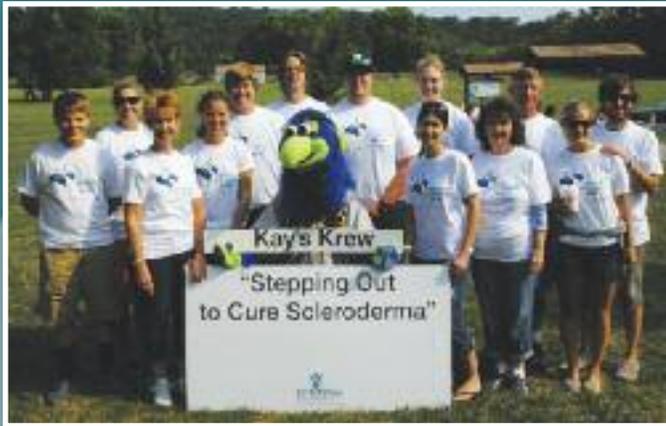


Place: John Rudy State Park – York, PA
Event: Stepping Out to Cure Scleroderma
Date: August 9, 2014
Attendees: 99
Funds raised: \$8,600

John Rudy Park was covered with morning dew that covers healthy meadows and luscious grasses.

This was my second visit to this magical place and vibrant walk, the first being my first weekend as Executive Director of the Scleroderma Foundation of the Delaware Valley.

With the usual, more than willing, volunteers showing up, they jumped into action putting up banners setting up the barbeque and covering tables. They put up sponsor signs and even the youngsters took part by blowing balloons and making sure the “kids table” was all set to receive willing participants. For those parents whose youngsters took part volunteering, please reach out to me so I can provide them with acknowledgments for their school files. It counts as community service and we are grateful for all their help. You can reach me at 856-779-7225 by phone or fsepahi@scleroderma.org.



This year we were joined by “DownTown”, the official mascot of the York Revolution baseball team. He made for some fun entertainment and got into many of the team photos which can be found on www.sfdv.org (Go to “Your Community”, then “Photo Gallery” and finally “2014 York Photos”).

We were honored to have some notable new teams join our walk from distances such as Pittsburgh and Luzerne County in the Poconos.

In 2015, we look forward to having a community of volunteers to help produce this walk in order to make a larger impact in the York county area. We have created a committee who will spearhead this effort. Please call 856-779-7225 or email me at fsepahi@scleroderma.org if you have any interest in participating on this valuable committee.



Thirteenth Annual Teri's Run and Twilight Walk

A fun-filled event, complete with \$\$\$ prizes, is held in Downingtown, PA the first Friday of September each year, in the memory of Teri Valocchi who lost her life to Scleroderma. Teri was an avid athlete with a habit of running during the twilight hours. It's in her honor and memory that organizers get together on this special night. The township and police close off Green Street at the intersection of Lancaster Avenue. The sponsors have donated all they can, the DJ strikes up some lively tunes and the kids get all wound up for their share of the activities – the kids run! The volunteers put out food,



drinks and hand out tech shirts to all registered and this timed 5k is set for another remarkable showing. Runners from as far as the Delaware Running Company and even further come to participate in this event which boasts a \$250 first place prize all the way to the 10th place winner! This year even the Philly Phanatic showed up to cheer on the mighty runners.

SFDV is grateful for the thousands of dollars this event has raised to further the efforts for research to find a cure for Scleroderma and we eagerly look forward to this event on September 4, 2015!

Team "Come on Ilene" *Submitted by Ilene Nusblatt*



Almost 7 years ago, I was diagnosed with a very aggressive form of Scleroderma. Afraid, I very quickly got involved in The Delaware Valley Chapter to learn as much as possible. The Philadelphia Walk was coming up. I wanted to go, but felt too overwhelmed. My daughter, Ava, who was then 10 years old, decided that she would create a team, design T-shirts, and raise money for The Foundation. I thought she would

need a lot of help, but it turned out I had very little involvement. She needed a way to support me and this was something she could do. She called my team "Come on Ilene"; She created blue and white team shirts and a banner for us. She always sings the Dexys Midnight Runners song at least once a day. She is

now 16 and a junior in high school. She has raised about \$20,000 for The Delaware Valley Chapter. Because of Ava, no matter how badly I feel on the day of the walk, or any other, I always push through. She motivates me to always try harder and to never give up. On walk day, the weather is always beautiful. Boathouse Row is always lovely in October. I always end up happy to be at the walk in order to be with those who can relate to the same difficult situation in such an uplifting environment. For us, this walk has become my daughter's "thing". With humility and emotion, she tells my story and asks for support. I am amazed by how much love and support we receive, when year after year people step up to help. Rare diseases fall by the wayside so I truly admire Ava and the other teams that walk to raise money and awareness. For Ava, this was never a whim. Her efforts with The Foundation are a part of who she is. Through thick and thin I am very grateful for her steadfast determination.

Joint Educational Seminar Held at Rutgers University



The annual effort between the Scleroderma Foundation's Tri-State and Delaware Valley Chapters was a Patient Education Forum held this year on October 25. About 40 people were in attendance at Rutgers University to listen to our guest speakers Dr. Robert Lahita and Dr. Laura Hummers.

Dr. Lahita, also referred to as Dr. Bob is a well-known physician and public figure. He is a Professor of Medicine at University of Medicine and Dentistry of New Jersey and an adjunct Professor at Mount Sinai School of Medicine and the Chair of Medicine and Vice President of the Newark Beth Israel Medical Center. Dr. Lahita's topic "Women, Scleroderma & Other Autoimmune Diseases - Why 80% of Autoimmune

Diseases Affect Women" was focused on something that we do not consider, very often, even though women with scleroderma outnumber men 4:1. Dr. Lahita was quite engaging and there were numerous questions after his presentation that he was more than happy to answer. Following Dr. Lahita's presentation, we welcomed Dr. Laura Hummers from Johns Hopkins University Hospital. Dr. Hummers works closely with one of the leading scleroderma experts, Dr. Frederick Wigley. She is an Assistant Professor of Medicine in the Division of Rheumatology and has been on the faculty at the Johns Hopkins Scleroderma Center since 2003. Her topic was "Scleroderma: The Importance of Early Intervention & Close Monitoring". Her presentation and her demeanor held the attention of each of us and she also followed her presentation with a lively question and answer session. We received very positive feedback from our attendees and look forward to working together to provide another program at Rutgers in 2015!

Support Group Meeting Locations

DELAWARE

Wilmington, Delaware (North Delaware)

Angie Crowl, 302-425-5054,
anglcrowl@aol.com
Every other month on Wednesdays – next
meeting on Jan. 21 at 6:30 pm
Woodlawn Library
2020 West 9th Street
Wilmington, DE 19805
302-571-7425

NEW JERSEY

Brick, New Jersey (Monmouth-Ocean County)

Marlene Stoeber, 908-278-8623,
MonmouthOceanSclerodermaF@yahoo.com
Once a month on Saturday at 10:00-12:00
pm
Brick Branch of the Ocean County Library
1st floor conference room
301 Chambers Bridge Road
Brick, NJ 08723

Cherry Hill, New Jersey (Burlington-Camden County)

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

PENNSYLVANIA

Ardmore, Pennsylvania

Donna O'Sullivan, 610-513-8882,
ardmoresclerodermagroup@gmail.com
3rd Thursday of each month at 7-8 pm
Allstate Insurance Company
19 Cricket Ave
Ardmore, Pa. 19003
610-658-3250

Doylestown, Pennsylvania

Desiree Blean, 215-249-1132,
doylestownscclerodermasg@gmail.com
Last Monday of the month, quarterly at 6:30
pm – March 30, June 29, September 28,
November 30
Doylestown Hospital
Conference Room G/H
(main entrance elevators to ground floor,
go right off elevator)
595 West State Street
Doylestown, PA 18901
215-345-2200

Philadelphia, Pennsylvania

Joyce Roby-Washington, 215-474-0259 or
267-516-6987, joycerw757@msn.com
2nd Wednesday of every other 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

Plymouth Meeting, Pennsylvania

Joan Evans, 215-699-2345,
sfplymouthmtg@gmail.com
3rd Monday of each month at 6:30 pm
Mercy Health Center
Plymouth Meeting Mall
500 West Germantown Pike
Plymouth Meeting, PA 19462

Reading, Pennsylvania

Dawn Batzel, 610-310-2566,
happy81070@verizon.net
2nd Saturday of every other month
at 10:00 am
Reading Pediatrics office
40 Berkshire Court, Wyomissing, PA 19610
610-374-7400

Williamsport, Pennsylvania

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
June and December meetings held at 1:00 pm
at Hoss's Steak House, 1954 E. Third Street,
Williamsport, PA



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

Central DE Area
Southern DE Area

New Jersey

Brick NJ (co-leader needed)
Cape May Area
Central NJ Area
Southern Shore Area

Pennsylvania

Carlisle/Harrisburg Area
Luzerne/Lackawanna County
York/Lancaster 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

March 14 – Educational Seminar, Southern NJ
April 25 – Race4Linda, Hershey Mills, PA
April 26 – Cruise for a Cure Car Show, Wilmington, DE
(rain date May 3)
May 2 – Stepping Out to Cure Scleroderma Walk, Ventnor, NJ
June – Stepping Out to Cure Scleroderma Walk,
Allaire State Park in Farmingdale, NJ
June – MacCutcheon/McTaggart Golf Outing, Rossmoor Golf Club,
Monroe, NJ

August – Stepping Out to Cure Scleroderma Susquehanna Valley
Walk, York, PA
September 4 – Teri’s Run & Twilight Walk, Downingtown, PA
October – Stepping Out to Cure Scleroderma Walk,
Philadelphia, PA
October – Educational Seminar at Rutgers University,
New Brunswick, NJ

*Check our website at www.SFDV.org for news and information.
Check out our Facebook page for frequent postings at www.facebook.com/SFDeVal*

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.SFDV.org

