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NEWSLETTER OF THE SCLERODERMA FOUNDATION DELAWARE VALLEY CHAPTER

Fall 2020

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**SCLERODERMA
FOUNDATION**
SUPPORT • EDUCATION • RESEARCH
DELAWARE VALLEY CHAPTER

385 Kings Highway North,
Cherry Hill, NJ 08034

For more information call the SFDV office at
866-675-5545
or email dvchapter@scleroderma.org

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From The Director's Desk Greetings from Darek!

At this point in time, as COVID-19 still dominates the news, I personally wanted to reach out and let you know that the health and safety of our scleroderma patients, volunteers, families, and supporters are our top priority. As so many of us are directly impacted by scleroderma, we know our community is especially vulnerable during this time of crisis and, with the upcoming flu season, the support given by you is even more vital than ever before. Due to this pandemic and in keeping everyone as safe and healthy as we can, we came to the difficult decision to transition our Walks from a live, in-person event to a virtual one. We are hopeful that this will not become the new norm for future events.

I was extremely disappointed to miss meeting each of you in person at our walks and events, those in-person meetings are what keeps me in the fight for better treatments and a cure for scleroderma.

*Actually talking to patients and families gives me
a greater sense of what it is we're all fighting
and puts both a name and a face to this disease.*

I know moving to a purely virtual event structure is the most responsible decision for our greater scleroderma community. With the new normal of social distancing, all our future events will go from what you have enjoyed in the past – meeting, greeting, and networking with other people who understand all too well what scleroderma is all about – to virtual.

We know. We get it. You are being pulled in many different directions as we all cope with the stressors associated with this current health crisis. Now it is more important than ever for your support.

For that reason, among many others, I would like to personally thank each and every one of you for your dedication to Scleroderma Foundation Delaware Valley during this challenging time. Your efforts make such a tremendous difference for individuals and families impacted by scleroderma.

By coming together, we will continue the fight against scleroderma!



The Scleroderma Foundation of the Delaware Valley proudly recognized June as Scleroderma Awareness Month. We celebrated Scleroderma Awareness Month across Philadelphia in June 2020!



The PECO Building displayed our Scleroderma Awareness message on June 6, 7, and 8. The light display atop 23rd and Market Street spread awareness from the PECO Building marquee across their iconic Crown Lights.

On June 20th, Boathouse Row in Philadelphia was lit up in teal to show support for patients and raise awareness for this rare disease. Passersby were treated to a spectacular view of the boathouses on the Schuylkill River aglow in teal.

World Scleroderma Day was on June 29th. This day was dedicated to getting loud, spreading the word and raising awareness. Thank you to everyone who spoke up and spread the word about the faces of scleroderma. We couldn't be successful without your voices.

First Annual No Show Gala

Not only was June 29th World Scleroderma Day, it was also the day of the Scleroderma Foundation of the Delaware Valley's First Annual No Show Gala! We hope you enjoyed staying in your own home for this fabulous virtual fundraiser.

Members were asked to donate the cost of what they estimated they would have spent had this been an actual in-person event. This socially distant gala didn't require a new dress, new shoes, or hiring a babysitter! Instead, donors celebrated amongst themselves and 100% of your gifts benefitted the Scleroderma Foundation.

Thank you for sharing photos NOT attending the gala. And a special thank you to donors who donated \$100 or more and earned a World Scleroderma Day t-shirt!



Scleroderma - Newly Diagnosed

Most of us are scared when the doctor tells us we have scleroderma. Unless you have known someone with the disease or have a medical background, you probably never even heard of it.

The word “scleroderma” comes from two Greek words and means “hard skin.” Scleroderma is a connective tissue autoimmune disease. Our immune system usually protects our bodies from invasion by bacteria, viruses, and fungi (germs.) When a person has an autoimmune disease like scleroderma, their immune system attacks the cells of their own body by mistake. In Systemic Scleroderma, these attacks cause damage to the vascular system and fibrosis in the skin and connective tissue within the body. This may lead to organ damage.



Morphea (localized scleroderma) is generally limited to the skin. Lesions occur and cause scar like changes to the skin. There may be circular shaped lesions or linear shaped lesions or both. In some cases, the scar like tissue may extend deep inside and involve muscle and bone. If a deep lesion is over a joint, this may cause trouble with mobility. Dermatologists treat Morphea. There is no cure; however, medications and treatments are used to keep lesions from growing and to stop the growth of new lesions.

Systemic Sclerosis (scleroderma) is divided into two categories: limited systemic and diffuse systemic. Rheumatologists call anyone with skin thickening on the trunk, chest, upper arms, upper legs, or basically anywhere, into the diffuse category. Those whose skin thickening is “limited” to the distal (lower) part of the arms, distal legs, and face are in the limited category.

In general, those with diffuse disease get sick more quickly. Skin thickening and internal damage may happen very quickly. The majority of changes will happen in the first 3 years and usually level off after. Those with limited scleroderma generally progress at a slower pace. Both types of patients can have serious complications from the disease. There is no cure for scleroderma, but there are treatments to help with symptoms.

About 95% of patients will have Raynaud's, which is a reaction to cold temperatures or stress which leads to spasms in the small blood vessels of the hands or feet. Since feet are usually in shoes, people generally notice Raynaud's in the hands when their finger(s) become red, then white, and then purple. Sometimes this is painful. The best ways to prevent Raynaud's include keeping the core (trunk and belly) of the body warm and reducing stress.

Almost everyone (about 80%) will have damage to the Gastrointestinal system. This system includes the food pipe (esophagus,) the stomach, and the intestines (guts.) Many patients develop some kind of problem with eating or with moving the bowels.

About 90% of systemic scleroderma patients will have a positive Anti-Nuclear Antibody of ANA. The pattern found helps rheumatologists have an idea of the most likely course of disease progression.

Meanwhile, breathe. Do the best you can. Remember to check the source and date of any article you read. The Scleroderma Foundation at www.scleroderma.org is a good source for medically reviewed information.

2020 Virtual Stepping Out to Cure Scleroderma Walks

Thank you to everyone who virtually attended the **Virtual Stepping Out to Cure Scleroderma Allaire Walk** on June 13, 2020! We told you we can't miss a step in fundraising this year and you did not disappoint! We are so thankful to you for helping us keep our promise to those affected by scleroderma. The donations you raised will fund our mission of support, education, and research.

While being physically apart, patients, supporters, and advocates came together online to raise critical funding to provide patients and families impacted by scleroderma. Eight teams registered for the Stepping Out Allaire Walk this year! Close to 200 donors raised \$13,650 to make a difference in the lives of patients living with scleroderma. All of the donations raised will be used to fund the patient-oriented mission of the Scleroderma Foundation.



Thank you to our Diamond National Sponsors, Actelion and Boehringer Ingelheim! Knowledge that all monies donated will be used to fund the 2020 Stepping Out to Cure Scleroderma Allaire walk and ultimately the patient-oriented mission of the Scleroderma Foundation.

Congratulations to our Allaire teams with the Most Money Raised from last year's 2019 walk:

- 1st place - Grandma Doris' Kids - \$3,912
- 2nd place - Sue's Crew - \$1,855
- 3rd place - Debbie - \$1,772



Congratulations to our Allaire teams with the most walkers:

- 1st place – Grandma Doris's Kids (49 walkers)
- 2nd place – Patty's Wild Orchids (5 walkers)
- 3rd place – Team Joan 2020 Virtual (3 walkers)



We loved all of your Virtual Stepping Out photos on our Facebook page. Thank you for sharing them. We are already looking forward to seeing you in 2021!

We did not let social distancing prevent us from coming together virtually on August 8th! Six teams and 75 donors participated in the **Virtual Stepping Out to Cure Scleroderma York Walk**. Thanks to all of you, we raised \$7,398 to find a cure in honor of those we've lost and those fighting right now. As Virtual Walkers, you are not only changing the history of this disease, but more importantly, you're improving the lives of patients today and tomorrow with your generosity.

A special thank you to Actelion, our 2020 Diamond National Sponsor. We are grateful to Boehringer Ingelheim, for also being a 2020 Diamond National Sponsor. We also need to thank Castle Creek BioSciences for being the 2020 Local Diamond Sponsor.

Thanks to all of you who donated so that the Scleroderma Foundation of the Delaware Valley can fund the researchers who are pioneering effective treatment options for patients. Because of your fundraising, the Scleroderma Foundation leads the development of landmark medical platforms to dramatically improve patient outcomes. Thank you and congratulations to the following York Teams:



Most Money Raised: (last year's 2019 walk)

- 1st place – Kay's Krew – \$8,806
- 2nd place – Julie's Jewels – \$1,408
- 3rd place – Jodi's Gang – \$1,040

Most Walkers by Team

- 1st place – Deb's Crusaders (11 walkers)
- 2nd place – Julie's Jewels (8 walkers)
- 3rd place – Atch's Angels (5 walkers)



We appreciate that you chose to join us virtually to show York how passionate and powerful our community is. Because of your support, we are one step closer to finding a cure for Scleroderma. We are already looking forward to Stepping Out to Cure Scleroderma York Walk 2021! We hope to see you next year!

The Scleroderma Foundation of the Delaware Valley held the **Virtual Stepping Out to Cure Scleroderma Philly Metro Walk** on September 13. It was a beautiful day for those that participated in their own socially distant walk. Several of our present and former board of directors' members celebrated the day at Cooper River Park in Pennsauken via Facebook Live.

The SFDV crew arrived at 10:30 with balloons, signs, and posters of this year's sponsors. Thank you to our National Diamond Sponsors, Actelion and Boehringer Ingelheim for returning again this year. Castle Creek BioSciences participated as a Local Diamond Sponsor and Penn Scleroderma Center was a Local Gold Sponsor of the Philly Metro Walk. The Cardiovascular Center and Premier Orthopaedics joined us as a Local Bronze Sponsors. The Philadelphia Hand to Shoulder Center rounds out the list as the Local Copper Sponsor. We are grateful for the support of our fabulous sponsors!



125 Virtual Walkers and 22 Teams participated in this year's virtual walk. Thank you to everyone who didn't miss a step this year! Thank you and congratulations to the following Philly Metro Teams:

Most Money Raised: (last year's 2019 walk)

- 1st place – Cimini – \$20,035
- 2nd place – Emma's One in a Million – \$15,445
- 3rd place – Susan's Striders – \$9,500



Most Walkers by Team

- 1st place – Emma's One in a Million (29 walkers)
- 2nd place – Team Bhagat (25 walkers)
- 3rd place – Team Kiyanna (13 walkers)



This year we held our first virtual raffle! Thank you to everyone who donated gift baskets and all of you who bought raffle tickets. Thanks to you, SFDV raised \$2,637 from the virtual raffle! We hope you had as much fun as we did participating. We are looking forward to having another virtual raffle in Spring 2021.

You raised \$51,484 (and counting) for the Virtual Stepping Out to Cure Scleroderma Philly Metro Walk. Your donations will fund our mission of support, education, and research. We are already planning some big changes for next year's walk. Check our Facebook page for updates!

Become a Giver of Hope With Recurring Donations

Monthly recurring donations are the easiest and most convenient way for you to give to Scleroderma Foundation Delaware Valley. They also provide a predictable source of income that we can count on to fulfill our mission.

So, what does it mean to be a recurring donor? It means that your credit card or bank account will be set up by Scleroderma Foundation Delaware Valley to be charged on a certain date every month according to your specific instructions. You can change or cancel your automatic withdrawal at any time.

A recurring gift is a sustainable source of support that Scleroderma Foundation Delaware Valley can count on throughout the year. Monthly giving is the most cost-efficient way to deliver your support.

If you have recurring gift questions or for any reason wish to adjust your recurring gift or change the credit card being charged, contact Darek Ragusa, Executive Director and we will gladly assist you.

Also, did you know that the CARES Act relief initiative now allows taxpayers to deduct up to \$300 of their cash donations to qualifying organizations without itemizing deductions?

Remember that the deduction only applies to cash donations made to qualified 501(c)(3) organizations, such as Scleroderma Foundation Delaware Valley.



Castle Creek Biosciences

Castle Creek Biosciences is Proud to be a sponsor of the Delaware Valley Chapter's "Stepping Out To Cure Scleroderma" York and Philly Metro Walks

Welcome To Our New Board Members

My name is **Nishi Bhagat** and I am 23 years old. I have been involved in and have volunteered at the annual Philadelphia Scleroderma walk for around 13 years.

I am a part of Team Bhagat, which was created in support of my mother, Neerja Bhagat, who battled Scleroderma for 22 years.

I am just starting my career as a Registered Nurse in Cleveland, Ohio.



I am really excited to be a part of the SFDV team and to spread awareness of Scleroderma!



My name is **Yvonne Collins**. I am thankful for all the support The Scleroderma Foundation has given me the past 2 years.



The resources on the website and the connections I have made at the support group has been a tremendous help as I learn about my diagnosis: Undifferentiated Connective Tissue Disease with Characteristics of Scleroderma. For years I had flare-ups which kept me from working, exercising, and trouble breathing and keeping my hands, feet, nose, and ears warm.

Thankfully, I have learned more about my body and the disease. I am grateful I am feeling good these days and able to breathe easier, stay warm, move, love and laugh every day.

When Kathy asked me to consider joining the board, I thought what better way to give back. I look forward to seeing people at virtual fundraisers.



Chelsea Simenhoff is an attending physician on the faculty of the Virtua Family Medicine Residency Program in Voorhees, NJ.

Originally from Los Angeles, Chelsea has lived in California, Michigan, Florida, Dominica, New Jersey, and now in Philadelphia, Pennsylvania. Chelsea's professional research interests include improving patient education and care.



In her free time, Chelsea enjoys volunteering, hiking, travelling the world with her husband, and mastering home improvement projects.



Dawn Batzel loves spending time with her family. I enjoy reading, painting, fishing, traveling, and relaxing at our weekend getaway down the shore.

I have had Scleroderma since I was a teenager, trying as it is, I enjoy LIFE and I live it to the fullest. I love to try to help others with our disease. I run a support group in Reading PA and enjoy volunteering with local events to help get the awareness out for Scleroderma. I am in the documentary Project Scleroderma: Beneath the Surface.

I have a full-time job in the Construction industry as a Project Assistant, issuing the contracts and working with billing etc., where I have worked for 17 years.

I joined the Scleroderma Board, as I have a passion to help others, and I feel with being a patient, and having compassion and knowledge of living with Scleroderma for over 30 years is a good benefit.



If your organization participates in giving through United Way, please select

The Scleroderma Foundation of the Delaware Valley

United Way # 391722

We greatly appreciate your support!



AMAZON Shoppers: Amazon will contribute a percentage of your purchase to the Scleroderma Foundation of The Delaware Valley, should you so choose. It's easy to do! In your browser, bookmark www.smile.amazon.com and log in with your Amazon account. Only the first time will they ask you who you want your purchases to benefit. Select Scleroderma Foundation of the Delaware Valley and anytime you come back to shop, it will already have saved your selection. Thank you for making a difference in helping us find a cure for scleroderma!



If you work for a company that provides matching gifts, in most cases you can **double** your donation by enrolling in your organization's matching gift program. Scleroderma Foundation of the Delaware Valley is a registered 501(c)(3) non-profit organization!

SUPPORT GROUP *Meetings*

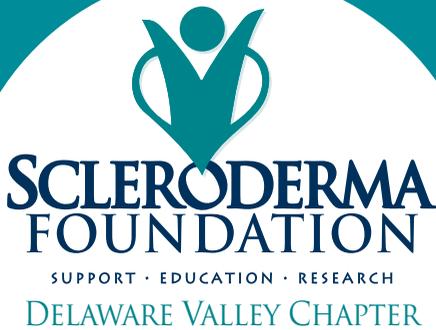
In-person support group meetings are suspended for the near future. Some groups may choose to have virtual meetings. Contact the Support Group Leader for further information.

VIRTUAL SUPPORT GROUP MEETING - OPEN TO ALL - Guest speaker: Chelsea Simenhoff, MD

October 27 at 6:00 - 8:00 pm for virtual telephone conference call meeting

Contact Support Group Leader for conference call number

Kathy Griffin, (c) 609-519-1770, kathyann3761@yahoo.com



Email Support Group

We have started an email support group for those patients and families who 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

Kathy Griffin is our new Patient & Caregiver Outreach Chair!



Kathy will be reaching out to patients and caregivers to learn how the Scleroderma Foundation of the Delaware Valley can best assist in providing information about our programs and services.

Meet Kathy!

"I am excited to begin my new role as the Patient and Caregiver Outreach Chair at SFDV. I was diagnosed with Scleroderma in 1995. Joining the Board of Director last year has strengthened my commitment to advocacy.

As the Support Group Leader for Camden and Burlington Counties, I enjoy helping patients access the resources they need to improve their lives. I am looking forward to assisting the patients and caregivers in the Delaware Valley."

Kathy is waiting to hear from you.
Please email her at kathyann3761@yahoo.com.
Kathy is a wonderful listener!

DELAWARE

Wilmington, DE (North Delaware)

Woodlawn Library 2020 West 9th Street | Wilmington, DE 19805 | 302-571-7425

Every other month from 6:00pm - 8:00pm.

Contact: Angie Crowl, 302-425-5054 or email: anglcrowl@aol.com

Dover, DE (Kent County)

Solid Rock Community Center 1st Floor Conference Room | 109 N. West Street | 302-734-1763

Contact Support Group Leader by phone or text:

Jennifer Cropper, 302-456-0959 or email: jennifercropper@gmail.com

NEW JERSEY

Brick, NJ (Monmouth-Ocean County)

Rainbow Diner 849 NJ-70 | Brick, NJ 08724

2nd Saturday of March, April, September, October, & November from 10:00am - 12:00pm

Contact: Marlene Stoeber, 908-278-8623 or email: mrslatte@comcast.net

Cherry Hill, NJ (Burlington-Camden County)

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

Meets virtually monthly on Tuesdays from 6:00pm - 8:00pm. Contact leader for information.

Contact: Kathy Griffin, 609-519-1770 or email: kathyann3761@yahoo.com

(turn into driveway at 383 Kings Highway North for Carelton Insurance and follow driveway behind building to Cherry Professional Building. 1st floor conference room)

PENNSYLVANIA

Doylestown, PA

Doylestown Hospital, Conference Room G/H, 595 West State Street | Doylestown, PA | 215-345-2200

(main entrance elevators to ground floor, go right off elevator)

Meets virtually on last Tuesday of every month from 6:30pm - 8:00pm (except June & August).

Contact: Kelly A. Kelly at 215-805-6680 or email: kelly.a.kelly@comcast.net

Enola, PA (Central PA)

Capital Blue Store 4500 Market Place Way | Enola, PA | 855-505-2583

First Wednesday of each month from 6:00pm - 7:00pm.

Contact: Michelle McPherson at 717-421-8325 or email: sclerocentralpa@yahoo.com

Reading, PA

Meeting at Office of Dr. Emkey 1200 Broadcasting Rd., Suite 200 | Wyomissing (Reading), PA 570-326-0838, or nearby location.

Meets virtually 2nd Saturday of every other month at 10:00am.

Contact: Dawn Batzel at 610-310-2566 or email: happy81070@verizon.net

Contact Support Group Leader via email to verify upcoming meeting location.

Williamsport, PA

Hoss's Steak House 1954 E. Third Street | Williamsport, PA | 570-326-0838

Meets 1st Wednesday of each month at 1:00pm.

Contact: Jayne Young at 570-323-4228 or email: weyejy@gmail.com, or Earl Ritter, 570-584-2407



Penn Scleroderma Center

The Penn Medicine Scleroderma Center is conducting a clinical research trial evaluating the efficacy of a drug called iloprost compared to placebo (no active ingredients) in decreasing the frequency and symptoms of Raynaud's phenomenon (RP) in people with scleroderma.

The study involves visiting the Penn Perelman Center for Advanced Medicine for a screening visit, infusion of study drug (IV) on 5 consecutive days, and 1 follow-up visit.

Participants will be compensated for their time. You may qualify if:

- You are a person who has RP and scleroderma
- During the screening period, have regular attacks of RP

To find out more about the study, please contact the research study coordinator, Hannah McCague, at Hannah.mccague@penntmedicine.upenn.edu, or 215-614-4426.

Site Principal Investigator: Peter A. Merkel, MD, MPH

**SPECIAL THANKS to the
Penn Scleroderma Center
for being a
Gold Sponsor
for the
Philadelphia Metro Walk!**

