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NEWSLETTER OF THE SCLERODERMA FOUNDATION DELAWARE VALLEY CHAPTER

Fall 2021

Greetings from Delaware Valley!

When COVID-19 hit, we pivoted to all virtual platforms, virtual walks, virtual support groups, virtual seminars, and virtual special events. Scleroderma Foundation of the Delaware Valley (SFDV) staff, volunteers and our Board of Directors worked tirelessly along with our community partners and sponsors to organize and offer these virtual events to keep the SFDV community connected and engaged. We are hopeful for us all to meet in the upcoming year at SFDV in-person events!

In this newsletter, we will highlight special moments from our Annual June Scleroderma Awareness Month to the virtual events which have been held this past year. You will learn about upcoming important dates and opportunities, including the best ways to give this holiday season and how you can support SFDV's mission. Your support helps us grow and thrive during these difficult times. Words cannot express our appreciation enough.

As the days grow colder and shorter, our hope is that you will all prioritize self-care and find joy in the little things, whether it be lounging inside with a good book and a hot cup of tea, spending quality time with family and friends, or taking a peaceful walk through the woods to appreciate the beauty of fall.



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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Boathouse Row in Philadelphia was lit in teal for



Scleroderma Awareness Month

COVID-19 Vaccine Study in Autoimmune Disease At Temple Call 267-514-5375

Trial Specifics

- **DISEASE INVOLVEMENT**
The trial is enrolling patients with lupus, rheumatoid arthritis or scleroderma.
- **VACCINE RESPONSE**
Patients must have had a low antibody response to their initial vaccine regimen to participate.
- **REQUIRED MEDICATIONS**
Patients must be taking mycophenolate, methotrexate, or a B-cell depleting therapy like rituximab or ofatumumab.
- **HELP US CLOSE THE GAPS**
To find out more visit our clinicaltrials.gov site by scanning the QR code below.



[ACV01 CLINICALTRIALS.GOV WEBSITE](https://clinicaltrials.gov)

ACV01 clinical trial investigating vaccine booster response in autoimmune disease patients.

Many autoimmune disease patients are at risk for COVID-19 infection because of the medications they take. These patients are now eligible to receive an additional dose of an mRNA COVID-19 vaccine.

However, there are **large gaps** in our understanding of who will benefit from an additional dose of vaccine and how to make it work better.

The Autoimmunity Centers of Excellence, sponsored by the National Institute of Allergy and Infectious Diseases, has opened a clinical trial called **ACV01** to address many of these questions.

As new information is learned, the ACV01 study will change to answer questions about more autoimmune diseases, other medications, and pediatric populations.

Help us learn as much as we can about the best way to help autoimmune disease patients protect themselves against COVID-19.

Please consider participating in the ACV01 study.

It is time to help us close the gaps.

**IF INTERESTED CONTACT:
267-514-5375 or lupus@temple.edu**

Letter from the Board President

As you are aware, the Scleroderma Foundation is one of the national organizations for people with Scleroderma, their families, and friends. You may not be aware that the Scleroderma Foundation was formed Jan. 1, 1998, by a merger between the United Scleroderma Foundation and the Scleroderma Federation.

The Scleroderma Foundation of the Delaware Valley is an Affiliate chapter. This means that our chapter has maintained its own independent board with fiduciary as well as planning responsibilities. We send 30% of our income to National in order to have access to the resources available and remain part of the SF. National uses our 30% income to support research grants, pay salaries, present the National Scleroderma conference and as needed to support the organization. In addition to the required 30% donation, each year the board recommends an additional amount which is sent to National for discretionary use.

Some chapters, such as the Texas Bluebonnet and Ohio Chapters, are National chapters. National chapters do not have their own separate 501(c)3 status. They do not maintain their own bank accounts and are not (ultimately) responsible for fiduciary matters.

At Leadership Day 2020, the Scleroderma Foundation presented its Strategic Plan. The plan's intention is to improve the success of our organization, in order to raise scleroderma awareness as well as to remain viable financially. We need to increase funding, especially for research. Research, like everything else, has become more expensive. In order to attract and retain new researchers, we must increase the amount of our research grants. The SF would like to have all chapters become National chapters.

If you would like to find out more about the Strategic Plan, visit the "Newsroom" section on the SF website. For the newsroom link, go to www.scleroderma.org and select "About Us" at the top of the page. Then select the "Newsroom" tab on the left side. To listen to a webinar about (an update of) the Strategic Plan, click the linked word "here" on the page.

As an Affiliate Chapter, giving up our 501(c)3 means losing autonomy and control of our finances in order to remain part of the Foundation. We are working with an Affiliate Group committee to try to retain some input regarding decisions which affect us and to improve communication between chapters and leadership.

Per regulations which govern non-profit organizations, directed donations must be used per donor intent. If you would like your donation to be used locally, please specify this (Delaware Valley Chapter) on your donation form and check. Also, if you prefer to direct all or part of your donation to research, specify "research (percentage)" on the form. Otherwise, donations will be used at the discretion of the national organization. It isn't necessary to direct your donation, but we wanted to let you know that this is an option. The Scleroderma Foundation has "four-star" status on Charity Navigator, which means it is an excellent charity.

The Scleroderma Foundation of the Delaware Valley remains grateful to all our donors and sponsors, past and present. Thank you so much for all you have done to support those with scleroderma and their significant others via your donations. We look forward to seeing everyone when it is safe to have an indoor event.

Sincerely,
Katie Higgins
SFDV Board President

Fundraising Highlights of 2021

2021 was another unique year of virtual fundraising as Covid19 continues to be a public health concern. However, we still needed to raise money to support our mission of funding research, providing educational programs, and offering patient supports such as virtual support groups. We found unique ways to stay connected as a community and to raise money for the Foundation while safely following CDC guidelines. In April, we held a virtual cooking demonstration with Jill Gilber of, "A Tasty Plate". Virtual guests learned how to make a three-course brunch meal they can replicate for family and friends. The event was met with rave reviews by nearly all attendees!



In June, we celebrated Scleroderma Awareness Month by having our three annual walks in one virtual event on Saturday, June 26. Walk participants virtually walked from their home, park, or neighborhood to honor the day. Members of the community shared photos and posters of themselves "Stepping Out to Cure Scleroderma". Although we wish we could walk together as a community, we were still able to achieve our fundraising goal. Because of our amazing team captains and generous supporters, we had our 2nd (and hopefully last!) successful season of virtual walks.



In the fall, we held two Cruise for a Cure car shows featuring a wide array of vintage and classic cars. We held our first car show in Blackwood, New Jersey with the help of Hot Rod Garage and board member, Kathy Griffin. Guests safely enjoyed music, raffle prizes, and wide array of vehicles to explore on what was a beautiful fall day to be outside. We hope to grow this event for years to come!



Just one week later, we held our 9th Annual Cruise for a Cure in Delaware City, Delaware to honor the memory of Al Cowl. Board member, Angie Cowl, hosts this event to honor her late husband along with the support of family and friends. Both car aficionados and novices alike could appreciate the assortment of unique cars. This year's Delaware Cruise for a Cure was held at a new location along the beautiful Delaware River and provided a wide space to safely gather outside. All in all, it was a fantastic day of fundraising and another beautiful tribute to honor our Al's memory.



We have a lot of exciting plans brewing for the upcoming year in 2022! If you or anyone you know is interested in helping to plan or volunteer at an upcoming fundraiser, please don't hesitate to reach out to me. Or if you just want to say hello and introduce yourself, my inbox is always open. Wishing you and your family a safe and peaceful fall and holiday season!

**PA Governor Tom Wolf
proclaims June as
Scleroderma Awareness
Month!**

Mindy Fingerman
Board of Directors, Chair of the Fundraising Committee
Mindy.Fingerman@gmail.com

Most Money Raised By Teams - 2021 Stepping Out to Cure Scleroderma Walks

Stepping Out To Cure Scleroderma - Allaire

- 1st Place - Grandma Doris' Kids - \$13,024
- 2nd Place - Sue's Crew - \$1,050
- 3rd Place - Dante - \$925

Total Raised - \$18,671

Stepping Out To Cure Scleroderma - Philadelphia

- 1st Place - Cimini - \$18,740
- 2nd Place - Bhagat - \$2,425
- 3rd Place - Rosie - \$1,660

Total Raised - \$38,403

Stepping Out To Cure Scleroderma - York

- 1st Place - Atch's Angels - \$1,860
- 2nd Place - Jodi's Gang - \$850
- 3rd Place - Vesnic Team - \$525

Total Raised - \$4,502

Our Annual Appeal

Dear Members, Family, and Friends,

Recently, the Scleroderma Foundation updated its mission statement. Although its general content is the same, I feel it is easier to remember:

The Scleroderma Foundation's threefold mission provides emotional support and disease education while funding innovative research to discover the cause, understand the mechanisms, and overcome scleroderma forever.

This year we saw neighbors helping neighbors after wildfires, hurricanes, floods, and tornadoes. We saw volunteers giving COVID vaccines, helping at food drives, and offering emotional support to those who were suffering. Scleroderma hits one's life like a bad storm. The whole family is affected.

It is hard to be heard amid the multitude. We need to speak up and show up to support the mission and each other. Show up and perhaps offer emotional support to the newly diagnosed. Or call a friend who is having a "flare." Speak up by writing to your elected officials. Attend a walk, a car show, or throw a garage sale and offer all or part of the proceeds to the Scleroderma Foundation.

Today I am writing to ask for your financial support. We can accomplish much more if we work together. We hope for a cure today, but if that isn't possible, we want to help the next generation. Please give generously. No one should meet the storm called scleroderma.

Thank you.

Katie Higgins

SFDV Board President

khiggins@scleroderma.org



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Deborah S. Dunn, Esq. and Stark & Stark are proud to support the *Stepping Out to Cure Scleroderma Virtual Walks* for the Scleroderma Foundation of the Delaware Valley.

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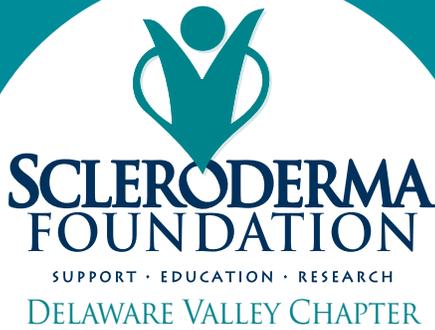
If your organization participates in giving through United Way, please select **The Scleroderma Foundation of the Delaware Valley** **United Way # 391722**
We greatly appreciate your support!



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.

Email Support Group

Do you belong to a Support Group?

Support groups provide a conducive setting to share concerns, information and feelings, in a confidential environment, where members provide encouragement, coping strategies and mutual support. While our in-person scleroderma support group meetings have been suspended for the near future due to covid-19, some groups are meeting virtually.

We also have an email support group for those patients and families who would like to participate online. Each week there is a weekly discussion topic sent by email. Everyone is free to respond to the topic or ask questions at any time. You can participate as little or as much as you like. If you have questions that you would like to be asked to the group, please let us know as we are always looking for more topics.

If you are interested in being part of our email support group, please contact the office at 856-779-7225 or email Colleen Ferara at cferara@scleroderma.org.

We hope you will consider joining our wonderfully supportive email group!

NEW Young Adults Virtual Support Group (age 18 – 30's)
Meets virtually first Thursday of the month from 7:30pm – 8:30pm. Next virtual meeting on December 2. Contact leader for Zoom link for virtual meeting: Amanda Lippincott at 908-328-3991, or via email Amanda.tufaro@gmail.com.

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 leader Angie Crowl at 302-425-5054 or via email: anglcrowl@aol.com.

Dover, DE (Kent County)

Contact Support Group Leader Jennifer Cropper at 302-456-0959 (phone or text) or via email: jennifercropper@gmail.com.

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 at 908-278-8623 or via email: mrslatte@comcast.net.

Cherry Hill, NJ (Burlington-Camden County)

Cherry Hill Professional Building - 385 Kings Highway North | Cherry Hill, NJ 08034 (turn into driveway at 383 Kings Highway North for Carelton Insurance and follow driveway behind building to Cherry Professional Building. 1st floor conference room).
Meets virtually monthly on Tuesdays from 6:00pm - 8:00pm.
Contact leader for information: Kathy Griffin at 609-519-1770 or via email: kathyannn3761@yahoo.com.

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 monthly on fourth Tuesday from 6:00pm - 7:15pm. Next Meeting December 28. Contact leader for Zoom link: Kelly A. Kelly at 215-805-6680 or via 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 7:00pm - 9:00pm. Contact Leaders for Zoom link for virtual meeting: Michelle McPherson at 717-421-8325 or via email: sclerocentralpa@yahoo.com / Dan Caruso at home 717-412-4050, cell 717-580-1440, or via email: raeprod@yahoo.com.

Reading, PA

Office of Dr. Emkey 1200 Broadcasting Rd. Suite 200 | Wyomissing (Reading), PA | 570-326-0838. Contact Leader via email to verify upcoming meeting location: Dawn Batzel at 610-310-2566 or via email: happy81070@verizon.net.

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 via email: weyejy@gmail.com, or Earl Ritter at 570-584-2407.

**385 Kings Highway North
Cherry Hill, NJ 08034**

For more information
call the SFDV office at

866-675-5545

or email

DVchapter@scleroderma.org

2022 *Events*

APRIL

9 **Cruise for a Cure NJ Car Show at Nifty Fifties**
Blackwood, NJ (Rain date April 10)

23 **Educational Seminar at Virtua**
Voorhees, NJ

MAY

7 **Cruise for a Cure PA Car Show**
Carlisle, PA (Rain date May 8)

21 **Educational Seminar at Lancaster General Health**
Lancaster, PA

SEPTEMBER

9 **Teri's Run & Twilight Walk,**
Downingtown, PA



Stepping Out To Cure Scleroderma Walks

JUNE 11 - Allaire State Park, Farmingdale, NJ

AUGUST 6 - John Rudy Park, York, PA

SEPTEMBER 10 - Cooper River Park, Pennsauken, NJ

(All Dates Are Pending)

www.SFDV.org for news and information.

Email us at DVchapter@scleroderma.org

Check out our Facebook page for frequent postings at:



www.facebook.com/SFDeIVal

Follow us on Twitter: [@SFDV1](https://twitter.com/SFDV1)

