

the PURSUIT

Every Step Counts
EDUCATE • ADVOCATE • CURE

Inside This Issue

From the Director's Desk	p 1
Capitol Hill Day 2019	p 2
Seeking Volunteers	p 2
State Report Cards	p 3
Penn Medicine Patient Education	p 4
2020 Stepping Out To Cure	p 4
Importance of Giving	p 5
Central PA Soup Cook-Off	p 6
2019 Stepping Out To Cure Walk	p 6
Giving Options	p 6
Support Group Meetings	p 7
2020 Events	p 8



**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

SFDV Board

Angie Crowl	President
Pat McCann	Vice President
Bill Cowan	Treasurer
Elaine Blodgett	Secretary

Board Members

Dr. Linda Bornstein Baum
Joan Forrer
Kathy Griffin
Katie Higgins
Diane Lucente
Matthew Fingerman
Mindy Fingerman
Nancy Waltermire

NEWSLETTER OF THE SCLERODERMA FOUNDATION DELAWARE VALLEY CHAPTER

Spring 2020

From The Director's Desk Greetings from Darek!

For many of you, this is my first opportunity to reach out and introduce myself. My name is Darek Raguza, and in December of last year I was hired to be the Executive Director of the Scleroderma Foundation Delaware Valley.

Although my primary role is to coordinate the work of our Chapter's Mission of Support, Educate and Research, I am also tasked with coordinating key work of the SFDV initiatives, advocacy, events, communications, marketing and grants.

I am very pleased to be working on behalf of the SFDV to increase the impact and footprint in the community we serve.

As the key staff member of SFDV, it is also my job to ensure we work together to make a difference for all scleroderma patients. Your past support by attending Educational Seminars and our special events throughout the years, means the world to patients and families. For that, we cannot thank you enough as all these events assist SFDV with its Mission of Support, Educate and Research.

I look forward to working alongside you to make a positive difference in the lives of those we serve. You can read about the current reach and impact of the SFDV in this issue of *The Pursuit*, with updates in future issues.

By working together, we can create the positive change to affect a lasting impact across the Delaware Valley. Thank you for all you do and for being part of the Scleroderma Foundation Delaware Valley Family!



June is National Scleroderma Awareness Month!

Boathouse Row in Philadelphia will be lit in teal on June 20, 2020!

Capitol Hill Day 2019



Scleroderma patients, caretakers, and advocates took over Capitol Hill on the morning of September 17th. This two-day event was sponsored by the National Scleroderma Foundation. Citizen lobbyists were tasked with lobbying for H.R. 3446 and S. 2477. These are identical bills in the U.S. House of Representatives and U.S. Senate, titled the National Commission on Scleroderma and Fibrotic Diseases Act of 2019.

SFDV Board Member Kathy Griffin and SFDV Event Coordinator Sara Lemma attended Scleroderma Capitol Hill

Day along with 49 citizen lobbyists from all over the country. The goal was to meet with state representatives and ask them to cosponsor the bills. The group met with legislative assistants from the offices of Senator Robert Menendez, Congressman Donald Norcross, and Senator Cory Booker.

SFDV hopes to bring more citizen lobbyists to Capitol Hill Day 2020. It is imperative that we have citizen lobbyists to represent each state. Increasing Capitol Hill Day turnout would enable us to cover more congressional districts. This is important as members of Congress prioritize requests that come from those they are elected to serve.

If traveling to Washington, DC is difficult, you are encouraged to meet with your members of Congress in their local district offices. In-district meetings during the August recess allow volunteers to engage with their elected officials at the local level. Advocacy requires year round engagement, and district office staff are always available to meet, even if Congress is in session. If you are interested in attending an in-district meeting or if you would like to attend Capitol Hill Day 2020, please email Sara Lemma at slemma@scleroderma.org. For more information, visit www.scleroderma.org and click on the *Become an Advocate* tab on the left.

Do you want to give back? WE NEED VOLUNTEERS!

Get involved with the Scleroderma Foundation of the Delaware Valley (SFDV)!

Our primary goal is to raise funds for our three-fold mission of support, education, and research. We are determined to improve treatment and ultimately find the cause of and cure for scleroderma and related diseases. To that end, we are seeking volunteers to amplify our efforts. SFDV believes each volunteer possesses unique attributes to achieve the goals of our mission. PLEASE JOIN US!

Please tear off and mail your response to:

Scleroderma Foundation of the Delaware Valley, 385 Kings Highway North, Cherry Hill, NJ 08034

Please check as many boxes of interest to you.

Name _____

Street Address _____

City _____

State _____ Zip _____

Phone Number _____

Email _____

- Support Group Leader
- Organize community education events
- Grant writing
- Meet with elected officials to spread awareness and raise funds
- Volunteer to table at a local community health fair
- Lobby legislators at Capitol Hill Day in Washington, DC
- Solicit local businesses for event sponsorships or donations
- Write an article for the SFDV Newsletter
- Host or sponsor a fundraiser
- Volunteer at a Stepping Out to Cure Scleroderma Walk

Questions? Please email our Event Coordinator, Sara Lemma: slemma@scleroderma.org or call (856) 779-7225.

Scleroderma... A Rare Disease!

On Monday, February 24, 2020, Scleroderma Foundation Delaware Valley (SFDV) attended the New Jersey Rare Disease Day held at the NJ State Museum in Trenton. In attendance were Executive Director, Darek Raguza, and Board Member, Kathy Griffin.

The event, hosted by the National Organization for Rare Disorders (NORD), showcased what NORD does as a non-government mission-based organization, advocating for the rare disease community to bring awareness and education as well as empowering patients and the organizations which serve them.

Since 2015, NORD has created a State Report Card project, which evaluates the efficiency on how states are assisting individuals with rare diseases. Besides evaluating the policies important to the rare disease community, the report also delves deeper into information how a state deals with Medicaid Eligibility, Out-of-Pocket Drug Costs, Step Therapy, Medical Nutrition, and Newborn Screening, grading each of these variables. **Below are the Report Cards for the states of Delaware, New Jersey and Pennsylvania.**

DELAWARE		Fifth Edition	STATE REPORT CARD
For additional information on the grading methodology, please visit the State of the States Report: rareaction.org/stateofthestates			
Medicaid Eligibility		Overall Grade: A	
	Eligibility for childless adults	A	
	Eligibility for parent of a dependent child	A*	
	Eligibility for pregnant women	A	
	Medicaid and/or Children's Health Insurance Program (CHIP) eligibility for children	B	
Medicaid Section 1115 Waivers		Overall Grade: Pass	
Delaware has not sought to use section 1115 waivers to enact provisions in its Medicaid program that would be harmful to the rare disease community.			
Out-of-Pocket Costs		Overall Grade: B	
	Prescription drug cost sharing protections	B	
Step Therapy		Overall Grade: B	
	Based on clinical practice	A	
	Timeline	A	
	Exception process	A	
	Categories of exceptions	A	
	Subsequent guidance from state	F	
Medical Nutrition		Overall Grade: C	
	Coverage requirements for commercial health plans	B	
	Covered disorders requirements for commercial health plans	C	
	Coverage requirements for state-run programs	D	
	Covered disorders requirements for state-run programs	C	
Newborn Screening		Overall Grade: B	
	Screening for RUSP core conditions	C	
	Adding RUSP core conditions to the state panel	B	
	Funding for program	A	
	Use of dried blood spots (DBS)	A	
	Follow-up	B	
	Quality of program	D	
	Advisory committee	A	
Rare Disease Advisory Councils	Delaware has not enacted legislation to create a rare disease advisory council.		
Individual Insurance Market Protections			
Pre-existing conditions protections: Delaware has a guaranteed issue law, requires the use of adjusted community rating and prohibits pre-existing conditions exclusions.			
Short-term, limited-duration and association health plans: Delaware limits the initial contract duration of short-term, limited-duration health plans to three months and prohibits issuance of more than one short-term, limited-duration plan during any given year. Delaware requires that an association form for a purpose other than offering insurance and be in existence for a minimum of five years before offering coverage. Fully-insured association health plans must comply with all laws and regulations applicable to small employer groups.			
Reinsurance: Delaware has obtained a section 1332 waiver to establish a reinsurance program. Delaware's reinsurance program has an attachment point of \$65,000 and will cover costs up to \$215,000 at a rate of 75 percent.			
*Although stated eligibility level for parents of dependent children would not warrant an "A", state has expanded Medicaid to enable individuals previously ineligible for Medicaid to become Medicaid eligible up to 138% eligibility FPL and, therefore, earns an "A".			
©2019-2020 NORD. All rights reserved. NORD®, its icon, tagline, State Report Card and Rare Action Network are registered trademarks for The National Organization for Rare Disorders. NORD is a 501(c)(3) charity organization. NRD-2021			

NEW JERSEY		Fifth Edition	STATE REPORT CARD
For additional information on the grading methodology, please visit the State of the States Report: rareaction.org/stateofthestates			
Medicaid Eligibility		Overall Grade: A	
	Eligibility for childless adults	A	
	Eligibility for parent of a dependent child	A*	
	Eligibility for pregnant women	B	
	Medicaid and/or Children's Health Insurance Program (CHIP) eligibility for children	A	
Medicaid Section 1115 Waivers		Overall Grade: Pass	
New Jersey has not sought to use section 1115 waivers to enact provisions in its Medicaid program that would be harmful to the rare disease community.			
Out-of-Pocket Costs		Overall Grade: F	
	Prescription drug cost sharing protections	F	
Step Therapy		Overall Grade: F	
	Based on clinical practice	F	
	Timeline	F	
	Exception process	F	
	Categories of exceptions	F	
	Subsequent guidance from state	F	
Medical Nutrition		Overall Grade: B	
	Coverage requirements for commercial health plans	A	
	Covered disorders requirements for commercial health plans	C	
	Coverage requirements for state-run programs	C	
	Covered disorders requirements for state-run programs	A	
Newborn Screening		Overall Grade: B	
	Screening for RUSP core conditions	B	
	Adding RUSP core conditions to the state panel	B	
	Funding for program	B	
	Use of dried blood spots (DBS)	A	
	Follow-up	A	
	Quality of program	C	
	Advisory committee	C	
Rare Disease Advisory Councils	New Jersey has not enacted legislation to create a rare disease advisory council.		
Individual Insurance Market Protections			
Pre-existing conditions protections: New Jersey has a guaranteed issue law, requires the use of adjusted community rating, prohibits pre-existing conditions exclusions and has an individual mandate in place.			
Short-term, limited-duration and association health plans: Underwritten short-term, limited-duration health plans are prohibited in New Jersey. Self-funded association health plans must comply with all insurance laws, and regulations applicable to self-funded health plans and fully-insured association health plans must comply with all insurance laws and regulations applicable to small group insurers.			
Reinsurance: New Jersey has obtained a section 1332 waiver to establish a reinsurance program. New Jersey's reinsurance program has an attachment point of \$40,000 and will cover costs up to \$215,000 at a rate of 60%.			
*Although stated eligibility level for parents of dependent children would not warrant an "A", state has expanded Medicaid to enable individuals previously ineligible for Medicaid to become Medicaid eligible up to 138% eligibility FPL and, therefore, earns an "A".			
©2019-2020 NORD. All rights reserved. NORD®, its icon, tagline, State Report Card and Rare Action Network are registered trademarks for The National Organization for Rare Disorders. NORD is a 501(c)(3) charity organization. NRD-2021			

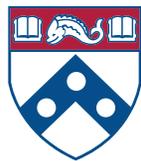
PENNSYLVANIA		Fifth Edition	STATE REPORT CARD
For additional information on the grading methodology, please visit the State of the States Report: rareaction.org/stateofthestates			
Medicaid Eligibility		Overall Grade: A	
	Eligibility for childless adults	A	
	Eligibility for parent of a dependent child	A*	
	Eligibility for pregnant women	A	
	Medicaid and/or Children's Health Insurance Program (CHIP) eligibility for children	A	
Medicaid Section 1115 Waivers		Overall Grade: Pass	
Pennsylvania has not yet sought to use section 1115 waivers to enact provisions in its Medicaid program that would be harmful to the rare disease community. Governor Wolf has vetoed two attempts to apply for a waiver to implement a work requirement.			
Out-of-Pocket Costs		Overall Grade: F	
	Prescription drug cost sharing protections	F	
Step Therapy		Overall Grade: F	
	Based on clinical practice	F	
	Timeline	F	
	Exception process	F	
	Categories of exceptions	F	
	Subsequent guidance from state	F	
Medical Nutrition		Overall Grade: C	
	Coverage requirements for commercial health plans	D	
	Covered disorders requirements for commercial health plans	C	
	Coverage requirements for state-run programs	C	
	Covered disorders requirements for state-run programs	A	
Newborn Screening		Overall Grade: C	
	Screening for RUSP core conditions	C	
	Adding RUSP core conditions to the state panel	D	
	Funding for program	C	
	Use of dried blood spots (DBS)	D	
	Follow-up	D	
	Quality of program	D	
	Advisory committee	A	
Rare Disease Advisory Councils	Pennsylvania enacted legislation to create a rare disease advisory council (RDAC) in 2017. Pennsylvania's RDAC published their first report to the state legislature in July 2018.		
Individual Insurance Market Protections			
Pre-existing conditions protections: Only current federal protections apply in Pennsylvania.			
Short-term, limited-duration and association health plans: Pennsylvania does not place any stricter limitations than current federal standards on short-term, limited-duration health plans. Pennsylvania requires that an association form for a purpose other than offering insurance and be in existence for a minimum of two years before offering coverage. Coverage sold to individuals and small businesses through an association must comply with individual and small-group market standards respectively. Self-funded association health plans must satisfy the same licensure and financial standards as commercial insurers.			
Reinsurance: Pennsylvania has not yet sought a section 1332 waiver to establish a reinsurance program.			
*Although stated eligibility level for parents of dependent children would not warrant an "A", state has expanded Medicaid to enable individuals previously ineligible for Medicaid to become Medicaid eligible up to 138% eligibility FPL and, therefore, earns an "A".			
©2019-2020 NORD. All rights reserved. NORD®, its icon, tagline, State Report Card and Rare Action Network are registered trademarks for The National Organization for Rare Disorders. NORD is a 501(c)(3) charity organization. NRD-2021			

As you can see, New Jersey excels at many areas, but is woefully inadequate when it comes to Step Therapy. In Pennsylvania, the same results are seen. Delaware does much better than either New Jersey or Pennsylvania and could definitely be a resource for both of those states. Delaware is not perfect, but they definitely have a better track record.

If we are to make real and meaningful progress, we must embrace the realities of rare diseases, including funding, awareness, and education. SFDV is working diligently in all three areas, making this disease front of mind for communities everywhere.

View Report Cards for all states, more background and an explanation of the grading methodology:
www.rareaction.org/resources-for-advocates/state-profiles/

Penn Medicine Patient Education Program



Penn Medicine

On Saturday, November 16, 2019, the Scleroderma Foundation of the Delaware Valley cosponsored an Educational Program with Penn Scleroderma Center at the Smilow Center for Translational, located at the Hospital of the University of Pennsylvania, Penn Medicine, in Philadelphia.

Four world renown physicians, experts in Scleroderma research and clinical care, spoke to 100 attendees comprised of patients, caregivers, and advocates.

Peter A. Merkel, MD, MPH is an internationally recognized research and clinical expert in vasculitis and scleroderma. Dr. Merkel, Chief, Division of Rheumatology, Professor of Epidemiology in Biostatistics and Epidemiology, at Penn Medicine, author of over 230 research works, provided an update of the clinical trials regarding Scleroderma at the Penn Scleroderma Center. He has been featured in Best of Philadelphia Magazine as a Top Doctor.

Nora Sandorfi, MD, Associate Professor of Rheumatology at Penn Medicine, has over 30 publications related to autoimmune disease. She specializes in Scleroderma diagnosis and management, connective tissue disease related interstitial lung diseases and idiopathic pulmonary fibrosis, and Sjogren's Syndrome. Dr. Sandorfi discussed exercise techniques for patients with scleroderma. She has also been featured in Best of Philadelphia Magazine as a Top Doctor.

Colin Ligon, MD, MHS, Assistant Professor of Clinical Medicine, has published over 15 clinical research articles. He works with Scleroderma patients with a focus on sarcoidosis, particularly musculoskeletal manifestations, extrapulmonary and cardiac disease, and situations of overlap with autoimmune disease. Dr. Ligon discussed the results from recent scleroderma research projects.

Chris Derk, MD, MS, Professor of Clinical Medicine, has 76 research items and expertise in Scleroderma and Systemic Lupus Erythematosus outcomes, therapeutic interventions, and disease pathogenesis. Dr. Derk has been featured as a Top Doctor in Best of Philadelphia Magazine.

The final portion of the meeting included a question and answer session. The uplink for this program is available on our webpage and social media. Please visit www.sfdv.org. Then go to the tab for Your Community and Video Gallery to view the video. You will find many other videos from past seminars here also.

Many thanks to the program coordinators:

- Sally Thompson, Clinical Research Manager at the University of Pennsylvania
- Linda J.B. Baum, O.D., Education Chair of the SFDV, Member of the BOD of SFDV and SF
- Pat McGann, Member of the BOD of the SFDV, Education Committee
- Kathryn Higgins, Member of the BOD of the SFDV, Education Committee
- Colleen Ferrara, Support Group Manager, SFDV, Sara Lemma, Event Coordinator, SFDV

The Scleroderma Foundation of the Delaware Valley (SFDV) and the Penn Scleroderma Center cosponsored this event. SFDV has no affiliation with any hospital or facility. We do not endorse medications or treatments and refer you to your physician for your care. We are pleased to provide materials and programs for your information.

Stepping Out To Cure Scleroderma Walk or 5k

Sign Up • Form A Team • Raise Funds

Look For An Event Near You!

www.sfdv.org

For more information call the SFDV office at

866-675-5545

or email DVchapter@scleroderma.org



Importance of Giving!

Charitable organizations such as Scleroderma Foundation Delaware Valley (SFDV), exist to support and raise funds for a specific group of people. There are numerous charities that support a wide variety of causes such as children in various locations, sufferers of various rare diseases, homeless people and disadvantaged people at home and overseas. SFDV depends on the generosity of the general community to make donations to charity of money, goods and services, in order that they can carry out their work. Many charities, such as SFDV, are completely self-funded while others receive some government funding.



Why is it important that we donate to charity? Here are just 5 good reasons:

1. **Help other people** – there are millions of people in the world who are worse off than we are at any one time. Many of these folks have problems that are not their fault or are beyond their ability to prevent or change. Humans are a social animal and the best way for mankind to advance is by helping those who are unable to help themselves. We have a responsibility to care for other people, to help those less fortunate than ourselves. When we have some spare cash, time or goods, it is an opportunity to help.
2. **Make a difference** – donating to charity is the perfect opportunity to make a difference in the world. By making a difference to someone's life, you are leaving behind a legacy. You are making a statement that your life was worthwhile because you contributed to society.
3. **Feel good** – medical and scientific research has proven beyond doubt that giving to other people makes you feel good. The feeling of satisfaction you get when you help someone else is hard to replicate with any other type of activity or endeavor. People who give feel happier, are less anxious and suffer less depression than those who don't. Better health is enjoyed by those who donate their time, expertise or money to others who are in need. Charitable people tend to be able to cope with their own problems more easily than those who don't donate. Giving to others improves your self-esteem, self-confidence and self-worth. This advantage flows into all areas of your life so you will find that you are more confident at work and in social situations.
4. **Support a cause you believe in** – different charities touch the heart of different people. If you are passionate about something or believe that a certain area is important, you will be able to support that cause by donating to charity. You might be passionate about every child having access to a good education; that nobody should live in poverty in the 21st century; that everyone should be able to experience music or art. Whatever you believe in or are passionate about, you will be able to further the cause through donations to charity.
5. **Meet new people** – donations to charity give you the opportunity to meet new people and expand your circle of acquaintances. This is especially true when you donate your time or expertise to a worthy cause. While most charitable organizations always need money, many could not operate without an army of volunteers. Whether you give up your time one day a week to serve meals, give a few hours a day to sit with the elderly or travel overseas to help build houses, you will certainly meet many like-minded people along the way. As well as being potential friends, who knows where these new relationships will take you and how these new people might be able to help you in the future?

So shed any doubts you have about why donations to charity are so important and offer your time or money to a cause you believe in. Many other people will benefit but you will also benefit in so many ways.

Sixth Annual Central PA Soup Cook-Off



The Sixth Annual Central PA Soup Cook-off was a success! Over 4,500 people attended the event at the Appalachian Brewing Company in Harrisburg, PA. The Renninger and Saunders families hold this fundraiser to celebrate the life of Kay Renninger, who passed away from scleroderma.

Professional and amateur chefs from local restaurants and the community entered their soups, chowders, chilis, and stews. Judges voted on their favorite soups, as well as the one they determined to be the most unique. Additional soups were awarded the prestigious "People's Choice" trophy in each division and "Best

Presentation" trophy as voted by guests.

Attendees raised over \$6,000.00 for scleroderma research. This family-friendly community event has something for everyone. In addition to sampling over 35 soups prepared by professional and amateur chefs, there was live music, raffles, and a 50/50 drawing.

The Seventh Annual Central PA Soup Cook-Off will be held on Sunday, September 20, 2020 at the Abbey Bar at Appalachian Brewing Company in Harrisburg, PA. Tickets can be purchased here:

www.eventbrite.com/e/7th-annual-central-pa-soup-cook-off-benefiting-the-scleroderma-foundation-tickets-96265806619

30th Annual Stepping Out to Cure Scleroderma Philly Walk

SFDV celebrated the 30th Annual Stepping Out to Cure Scleroderma Philadelphia Walk on September 8, 2019 at Memorial Hall. The walk was held in memory of SFDV's former Board President, Neerja Bhagat.

The morning was filled with lots of excitement as volunteers arrived before dawn to help set up the Walk. Once the sun came up, volunteers greeted participants, registered attendees, distributed t-shirts, and sold raffle tickets.

Neerja's son, Deepak, cut the ribbon signaling the start of the walk. West Fairmount Park was taken over by a sea of teal as over 350 walkers made their way through the course. Attendees cheered on participants as they began and finished the walk.

After the walk, attendees enjoyed refreshments and even balloon animals! Neerja's friend, Sue Serio, who serves as the weather anchor on Good Day Philadelphia, announced raffle winners, and closed out the event.

On behalf of SFDV, thank you to everyone who participated in, donated, sponsored and/or volunteered! We hope you will join us again at our new location in 2020. The 31st Annual Stepping Out to Cure Scleroderma Philly Metro Walk will be held on September 13th at Cooper River Park.



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.



SUPPORT • EDUCATION • RESEARCH
DELAWARE VALLEY CHAPTER

SUPPORT GROUP *Meetings*

Support groups provide a forum to share feelings, concerns and information, as well as a place to offer peer support and encouragement. Solicitations or research projects are not conducted at support group meetings. Support groups often feature speakers specializing in scleroderma or related topics.

To find out information about upcoming speakers or meeting topics, please contact the support group leader or chapter office.

This schedule is subject to change. Before attending a group for the first time, please call to verify date and time. Groups are free of charge and open to everyone.

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

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.

New Jersey

Cape May area / Southern shore area

Central NJ area

Pennsylvania

Carlisle / Harrisburg area

Luzerne / Lackawanna County,

Plymouth / Norristown area

Philadelphia

York / Lancaster area

DELAWARE

Wilmington, DE (North Delaware)

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

Every other month on Wednesdays from 6:00pm - 8:00pm. Next meeting in May!

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

NEW JERSEY

Brick, NJ (Monmouth-Ocean County)

Rainbow Diner 401 Chambers Bridge Road | Brick, NJ

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

Next meeting on September 12!

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

Meets monthly on Tuesdays from 6:00pm - 8:00pm.

Contact: Kathy Griffin, 609-519-1770 or email: kathyan3761@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 last Tuesday of every month from 6:30pm - 8:00pm. Next meeting May 26th!

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. Next meetings June 3rd & July 1st!

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

See Event Calendar on page 8 for Support Group Events.

Reading, PA

Office of Dr. Emkey 1200 Broadcasting Rd., Suite 200 | Wyomissing, PA | 570-326-0838

2nd Saturday of every other month at 10:00am. Next meeting July 11th!

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

1st Wednesday of each month at 1:00pm. Next meeting June 3rd!

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

2020 Events

JUNE

- 6** Central PA Honor the Fight for Scleroderma Luncheon
Upper Darby, PA
- 13** Stepping Out to Cure Scleroderma **Virtual Walk**,
Allaire State Park, Farmingdale, NJ
- 14** Julia's Kickin' Scleroderma 5K Run and Walk (Postponed to Fall 2020)
Chalfont, PA
- 14** Central PA Fundraiser at Hoss's Steak & Sea House - Enola, PA

JULY

- 17-19** National Scleroderma Patient Conference - Seattle, WA

AUGUST

- TBD** Annual White Party, Sea Isle City, NJ
- 8** Stepping Out to Cure Scleroderma Walk,
John Rudy Park, York, PA

SEPTEMBER

- 11** Teri's Run & Twilight Walk, Downingtown, PA
- 13** Stepping Out to Cure Scleroderma Walk
Philadelphia Metro Walk, Pennsauken, NJ
- 20** Central PA Soup Cook-Off, Harrisburg, PA

OCTOBER

- 3** Cruise for a Cure (Rain Date: October 4th)

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)

