

# the PURSUIT

Every Step Counts  
EDUCATE • ADVOCATE • CURE

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NEWSLETTER OF THE SCLERODERMA FOUNDATION DELAWARE VALLEY CHAPTER

Spring 2021

## From The Director's Desk Greetings from Darek!

I'm looking for a hero. And I think that may be you. I'll explain.

The Scleroderma Foundation Delaware Valley will host its Virtual Stepping Out to Cure Scleroderma in York, PA, Allaire, NJ and the Philadelphia Metro area. This event is our key fundraiser for the year.

To meet our goal and end the year on target, we need to raise \$72,000 by June 30, 2021.

"Wow," I can hear you saying, "that's a lot of money!" And it is, especially with all the challenges of the past year. But together we can raise it. Which is why I need a hero like you. I'm not asking you to do anything dramatic. You don't have to raise all of it yourself or put the touch on all your friends for support. All I need from you is just a donation. A simple donation. Maybe \$25, \$50, or even \$100 – any amount that makes sense for you.

### Here's what your gift will do:

- *Help patients and their families cope with Scleroderma through mutual support programs, peer counseling, physician referrals, and educational information*
- *Promote public awareness and education through patient and health professional seminars, literature, and publicity campaigns*
- *Stimulate and support research to improve treatment and, ultimately, find the cause and cure of Scleroderma and related diseases.*

I can't think of a more important cause than that! Let me assure you — we're well along the path to long-term financial health. In fact, our financial footing is more solid day by day. We're about to close the books on this financial year and we need to end the year strong. I know we can do this. I know because of friends like you.

People who want to find a cure for scleroderma; who understand we must keep up awareness for this rare disease.

It's up to us ... there isn't someone else out there to take this job!

You? You? You? How about you? Can you be the hero we need? Are you ready? Because that's how we'll meet this challenge. Will you send a gift today, please?



**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](mailto:dvchapter@scleroderma.org)

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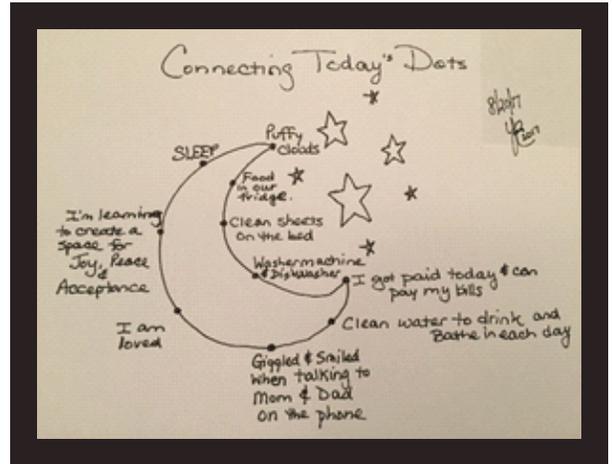
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# How did I deal with getting a new diagnosis of Scleroderma? by Yvonne Collins

At first, I felt confused, scared, exhausted, and felt like I was in limbo...

It seems I was sick for many years. Chronic allergies, sinusitis, sinus headaches, asthma, skin rashes, fluctuating hearing loss, heart palpitations, shortness of breath, laryngitis or raspy voice. In my 40s I was diagnosed with vocal cord dysfunction & silent reflux. Several years later I was diagnosed with Raynaud's Syndrome.

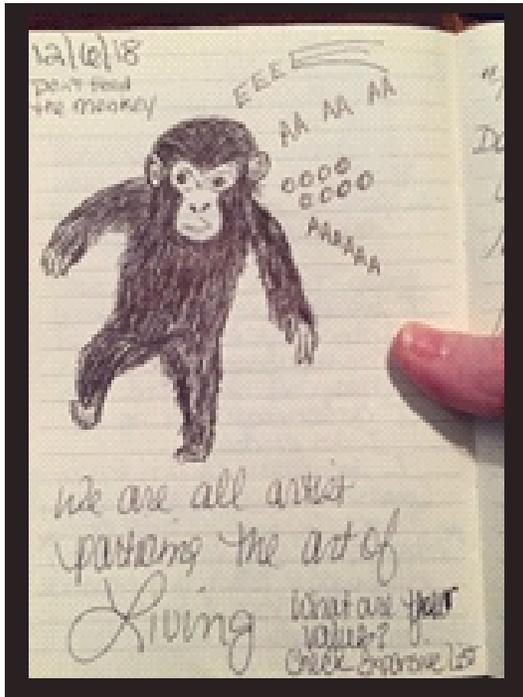
I will be forever grateful for my allergist who started to put the pieces together. He recommended me to see a rheumatologist to rule out an autoimmune disease because my allergies were so severe.



When I was first diagnosed, I listened to my first rheumatologist who said, "don't look Scleroderma up on the internet because it will scare you. Read the packet I will give you about Scleroderma". As I read the 3-page-packet, I cried and became anxious about what could happen to my hands, lungs, heart and skin. I cried and worried a lot wondering how I would be able to continue doing what I love to do. I was in denial and a state of confusion. After more tests, two hospital stays, supplemental oxygen at home, and more time for healing I went for a second opinion. The second rheumatologist helped me discover I have Undifferentiated Connective Tissue Disease with Characteristics with Scleroderma.

Again I found myself in limbo...what the heck does this diagnosis mean now... and for my future??? While I began to learn more about the diagnosis, I decided to continue to learn ways to take care of myself each day.

Thankfully, before my diagnosis, I was already on a journey of becoming my own best friend. I began to explore Restorative Yoga, Yoga Nidra, and Meditation apps: Stop-Think-Breathe app and The Calm app. I read a book titled: *We: A Manifesto for Women Everywhere* (by Gillian Anderson and Jennifer Nadel) which taught me many tricks including: Connecting Today's Dots and How to Make a List of My Inner circle activities to help me remember activities that brought me joy.



Even though I read about the benefits of "Gratitude Journals" I honestly found "Gratitude Journals" boring. The Inner Circle activity reminded me I use to love drawing. I decided to adapt my gratitude journal by adding my own drawings or color a picture while I listed what I was thankful for, meditations I was learning, and inspiring quotes from movies, meditation apps, or books.

I found a therapist I trust and work well with (I tried several other therapists prior until I found my current therapist.) She recommended I read the book: *Don't Feed The Monkey Mind* by Jennifer Shannon. This book was extremely helpful. My therapist continues to encourage me to sketch what I am learning to help my brain make new connections.

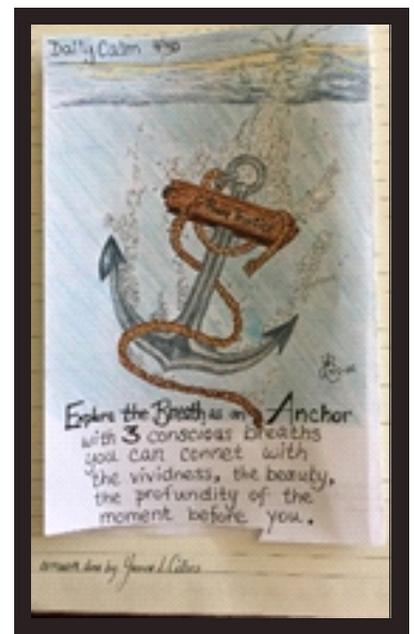
I displayed my art around my house or saved them on my phone's locked & home screen to show gentle reminders every time I picked up my phone.

I began to learn ways to **keep balancing** between emotions, doctor appointments, family time, me time, exercise, play time, work, & chores.

I figured when life seemed too busy to meditate, I could borrow tricks from Mr. Miyagi. In the 1984 movie *The Karate Kid*, Mr. Miyagi teaches Daniel karate by focusing on how to breathe and find peace while doing daily chores. This was extremely helpful because I didn't feel like I had enough time to complete my "Daily To Do List"; let alone add time to meditate. I didn't necessarily want to learn karate but the idea of finding more peace and less stress during daily chores and work sounded inviting.

I began to meditate during my breathing treatments which resulted in me meditating 2-3 times a day.

I learned I could slow down and practice meditating while I went for a walk, while cooking, cleaning, coloring, and while in a waiting room. Listening to the meditation apps helped me realize how often my forehead, eyebrows, jaw, shoulders, and stomach was tight while I focused on daily chores. Practicing meditation while completing chores helped me learn to relax my different body parts possibly decreasing stress and avoiding a Raynaud's flare.



Most importantly I began to listen to my body. If I am tired, I rest. If I have energy, I spread out visiting people, shopping, cleaning, cooking, laundry, working, exercising throughout the week. No more marathon cleaning, cooking and exercise in one day. Instead of working 4 -10 hour days... I began to work 5 days a week.

My wish for those reading this article: Hang in there. Reach out for support from families, friends, doctors, and the Scleroderma Foundation. Most importantly may you find something that brings you joy, hope, and peace every day. I am thankful I took an old hobby and connected the dots to my meditation and mindfulness journey.

# Virtual Stepping Out To Cure Scleroderma Walks

Allaire / York / Philly Metro

June 26, 2021

Sign Up • Form A Team • Raise Funds

For more information call the SFDV office at

**866-675-5545**

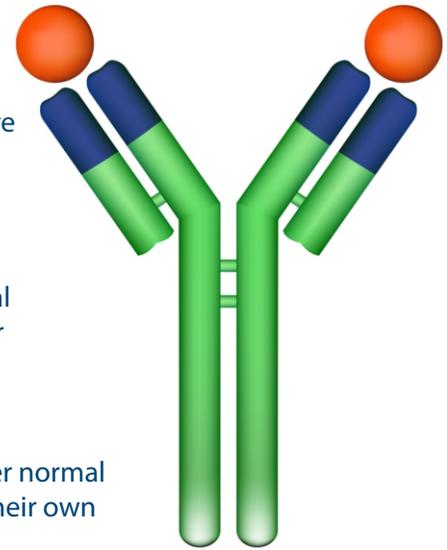
or email [DVchapter@scleroderma.org](mailto:DVchapter@scleroderma.org)

[www.sfdv.org](http://www.sfdv.org)



# Antibodies by Katie Higgins

Systemic Sclerosis, or Systemic Scleroderma, is diagnosed using various criteria, including the presence or absence of autoantibodies. 95% of scleroderma patients have at least one autoantibody. Over time, with research and observation, it has been determined that certain antibodies have a predictive value. That is, those with certain antibodies tend to have certain types of health issues.



Natural autoantibodies occur as part of the immune system and are mainly IgM (immunoglobulin M.) They provide a first line of defense against infections, probably serve housekeeping functions and contribute to the homeostasis of the immune system.<sup>1</sup> Natural autoantibodies, in other words, help get rid of infected, abnormal, and dead cells within our bodies as part of the immune response.

Autoantibodies are antibodies that react with self-antigens. An exogenous antigen that is recognized as non-self by the immune system, which should be considered otherwise under normal conditions.<sup>11</sup> The person with an autoimmune disease essentially attacks normal parts of their own cells.

Anti-centromere antibodies are considered the most common antibodies in scleroderma, associated with limited systemic scleroderma. Discovered in 1980, the antibody is relatively specific to scleroderma, but can be found in those with SLE, Sjogren's, Raynaud's and primary biliary cirrhosis.<sup>11</sup> Patients with limited disease tend to get organ involvement in a slower manner than those with diffuse disease. About 20-30% of those with anti-centromere antibody will get pulmonary arterial hypertension, which is a serious complication.

Anti-RNAP I and III antibodies almost always coexist and are considered highly specific for SSc. Anti-RNAP II are found in SLE and overlap syndrome and is not considered specific to scleroderma. It is estimated that about 11% of patients have Anti-RNAP antibodies. Anti-RNA polymerase III patients have diffuse disease and are at risk for renal crisis (see chart.)

Anti-U3RNP antibodies are detected in 4–10% of SSc patients are more frequently found in African American patients than in Caucasian or Asian SSc patients. Patients have frequent visceral (soft internal organ) involvement, especially the heart and kidneys.

Anti Th/To antibodies occur in 1-13% of patients and produce limited systemic disease with a poor prognosis due to association with pulmonary fibrosis and renal crisis.

Anti-U11/U12 RNP antibodies have been described in 3.2% of SSc patients. Raynaud's phenomenon, gastrointestinal involvement, and severe pulmonary fibrosis can lead to a higher risk of mortality.

15–42% of SSc patients have the ATA, or anti-topoisomerase antibody. This antibody, which causes diffuse disease, carries a poor prognosis related to pulmonary fibrosis and heart involvement.

“Other autoantibodies, including anti-U1-RNP, anti-PM-Scl, anti-Ku, anti-Ro60/SS-A, anti-Ro52/TRIM21, and anti-NOR 90 tend to be found in SSc-overlap syndromes as well as in other ARD, and are considered less specific for SSc.”<sup>111</sup>

What does this mean? Will everyone follow the table and end up with these problems if they have a certain antibodies? Not necessarily, however, the probability of certain issues occurring in those with certain antibodies gives the provider guidance to try to catch problems in the early stages. The medications we do have work best when started before damage is done.

If you are at risk for renal crisis, you should check your blood pressure daily and ask your provider for guidance about what should be reported immediately and what can wait until your next scheduled visit. Labs help guide decision making; don't forget to get your labs.

Pulmonary function tests are not fun in general, but they are very important. They are useful to determine if a right heart catheterization is necessary to diagnose early pulmonary hypertension. Quality of life is much better if problems are caught early.

Those at risk for cardiac issues should have routine cardiac testing and follow-up with cardiology.

Unfortunately, scleroderma has no cure, and we have few medicines which can reverse the damage done by the disease. We must strive to remain hopeful in the face of difficult odds. By learning about scleroderma and by working with our healthcare providers to optimize what is possible, we do the best we can. We are all more than our disease.

<sup>1</sup> Elkon, Keith, and Paolo Casali. "Nature and functions of autoantibodies." Nature clinical practice. Rheumatology vol. 4,9 (2008): 491-8. doi:10.1038/ncprheum0895

<sup>11</sup> <https://www.biologyonline.com/dictionary/self-antigen>

<sup>111</sup> Autoantibodies in systemic sclerosis: unanswered questions Cristiane Kayser1\* and Marvin J. Fritzler2 1 Rheumatology Division, Escola Paulista Medicina, Universidade Federal de São Paulo, São Paulo, Brazil Faculty of Medicine, Cumming School of Medicine, University of Calgary, Calgary, AB, Canada

	TYPE	CLINICAL ASSOCIATIONS	PROGNOSIS
<b>Anti-centromere</b> also called CENP	lcSSc - limited cutaneous systemic sclerosis	PAH - Pulmonary Arterial Hypertension	Better prognosis
<b>Anti-Th/To</b>	lcSSc	Pulmonary fibrosis, renal crisis	Poor prognosis
<b>Anti-U1-RNP</b>	lcSSc	Raynaud's phenomenon, puffy fingers, arthritis, myositis, overlap syndrome (i.e., MCTD)	Better prognosis
<b>Anti-PM-Scl</b>	Overlap with polymyositis lcSSc	Raynaud's phenomenon, arthritis, myositis, pulmonary involvement, calcinosis, sicca symptoms	Better prognosis
<b>Anti-hUBF (NOR 90)</b>	lcSSc	Mild internal organ involvement	Better prognosis
<b>Anti-topoisomerase I</b> Also called ATA	dcSSc - diffuse cutaneous systemic sclerosis	Pulmonary fibrosis, Heart involvement	Poor prognosis
<b>Anti-RNA polymerase III</b>	dcSSc	Renal crisis, tendon friction rubs, synovitis, myositis, joint contractures	Increased mortality
<b>Anti-U3RNP (fibrillarin)</b>	dcSSc	Renal crisis and cardiac involvement	Poor prognosis, especially in African Americans
<b>Anti-U11/U12 RNP</b>		Raynaud's phenomenon, gastrointestinal involvement, lung fibrosis	Increased mortality
<b>Anti-Ku</b>		Myositis, arthritis, and joint contractures	
<b>Anti-Ro52/TRIM21</b>	Association with other autoimmune diseases	Older age onset, pulmonary fibrosis	



The Race 4 Linda 5K and 1-mile fun walk is organized by volunteers to honor the memory of Linda Hayman who passed away in 2009. Since 2014, the Race 4 Linda all-volunteer team has educated our geographic community about scleroderma and celebrated the resiliency and tenacity of the scleroderma community.

**Over the past seven years, the race has raised more than \$50,000 to support the Scleroderma Foundation's research mission. One hundred percent of funds raised from Race 4 Linda were put towards research.**

**Thank you for your support!**





## Diagnosed with localized scleroderma or morphea that is difficult to control/resistant to treatment?

You may be interested in participating in a Phase 1/2 clinical research trial for an experimental gene therapy.

- Participant must be at least 18 years of age or older
- Study-related dermatologic examination and laboratory studies performed at no charge
- Investigational medication supplied for this 52-week study
- Reimbursement provided for travel and/or out-of-pocket expenses for qualified participants

To learn more, contact Paddington Testing Company, Inc. at 215-563-7330.

More information is available at <https://clinicaltrials.gov/ct2/show/NCT03740724>

## June Is Scleroderma Awareness Month



**Boathouse Row in Philadelphia will be lit in teal on June 6th**



# 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 Ferrara at [cferara@scleroderma.org](mailto:cferara@scleroderma.org).

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

Check out our Facebook page for frequent postings at:

[www.facebook.com/SFDeVal](https://www.facebook.com/SFDeVal)

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

[www.SFDV.org](https://www.SFDV.org) for news and information.

Email us at [DVchapter@scleroderma.org](mailto:DVchapter@scleroderma.org)

**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 June 3. Contact leader for Zoom link for virtual meeting: Amanda Lippincott at 908-328-3991, or via email [Amanda.tufaro@gmail.com](mailto: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](mailto: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](mailto: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](mailto: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](mailto: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 - 7:30pm.  
Contact leader for Zoom link: Kelly A. Kelly at 215-805-6680 or via email: [kelly.a.kelly@comcast.net](mailto: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](mailto:sclerocentralpa@yahoo.com) / Dan Caruso at home 717-412-4050, cell 717-580-1440, or via email: [raeprod@yahoo.com](mailto: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](mailto: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](mailto:weyejy@gmail.com), or Earl Ritter at 570-584-2407.

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Cherry Hill, NJ 08034**

For more information  
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**The Scleroderma Foundation of the Delaware Valley**

**United Way # 391722**

We greatly appreciate your support!



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!



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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!