



SCLERODERMA EXCHANGE

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Scleroderma Foundation Tri-State, Inc. Chapter
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MISSION

To provide educational and emotional support to people with scleroderma and their families
To stimulate and support research designed to identify the cause of and cure for scleroderma as well as to improve methods of treatment
To enhance the public's awareness of this disease

2019 National Patient Education Conference

In July, the 2019 National Conference was held in Chicago with a record-setting attendance of 700 patients, family members, caregivers, healthcare professionals and foundation leaders. The Tri-State chapter was well represented with 42 attendees. The three-day event featured 55 scleroderma experts and researchers as well as patient presenters, including 6 from our region. There were 60 sessions this year with 15 focused on juvenile scleroderma in the *Kids Get Scleroderma, Too (KGS2)* program. Fourteen of the sessions were video-taped and are available online at www.YouTube.com/sclerodermaUS.

At the Saturday luncheon, the Foundation recognized significant achievements by individuals and chapters. We are proud to share with you that two awards were presented to Tri-State members this year.

Jessica Farrell, Pharma D. was the 2019 recipient of the **Doctor of the Year** award for her work in securing off-label usage of the



immunosuppressant drug CellCept® (mycophenolate mofetil) for treating scleroderma. Dr. Farrell is a clinical pharmacist and associate professor at the Albany College of Pharmacy and Health Sciences.

This is important because the drug has shown in multiple

studies to lower measures of skin thickening and to have a stabilizing effect on lung involvement in systemic sclerosis. Dr. Farrell is uniquely familiar with the challenges of getting off-label use of prescription therapies approved by insurance. Thanks to her work there is one less roadblock on the path to treatment for scleroderma patients. On September 14th, Dr. Farrell spoke at the Albany Education Forum on "Medications in Scleroderma" you can watch a video of this talk on www.sclerodermavideo.com.

The **Messengers of Hope** award was presented to a mother, **Christina Locke** and her daughter **Claudette Johnson** for their continuing efforts and video to raise awareness about scleroderma and how it affects their family. The video won second prize in a national competition sponsored by the National Institute of Health (NIH)



in recognition of Rare Disease day. By sharing her story publicly, Claudette reminds us that in the land of rare diseases, half the citizens are children, and they deserve a chance to get better. Claudette and Christina are real champions for pediatric related research and awareness, taking their story to Capitol Hill with other scleroderma advocates and rallying family and friends for the Ridgefield Park, NJ Stepping Out to Cure Scleroderma Walk each June. Christina was recently appointed to the National Board of the Scleroderma Foundation where she will continue to champion for juvenile scleroderma issues. You can view Claudette's video at <https://bit.ly/2VY8Sc5>.



We gathered many of our Tri-State members together at the conference to connect. Tri-State had a great turnout as you can see by our group photo above. **Mark your calendar for next year!**

Save the Date

July 17-19, 2020 | Seattle, WA

Scleroderma Foundation National Patient Education Conference



Scleroderma Foundation Tri-State, Inc. Chapter

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A Message from Our Executive Director

This issue of the Exchange summarizes some of your activities in 2019 and offers opportunities for your future efforts within your Tri-State scleroderma community.

- *The national conference continues to expand, offering the latest updates on research and treatment options as well as ways to cope with your disease. If you were not able to attend, there are 14 sessions available on [YouTube.com/SclerodermaUS](https://www.YouTube.com/SclerodermaUS).*
- *Our advocacy efforts are in full forward mode with both a house bill and a senate bill introduced this year. The following article on the accompanying page offers details and action steps.*
- *Tri-State's support groups and educational forums are a valuable resource and a great opportunity to connect with other scleroderma warriors.*
- *Together we continue to find new opportunities to fundraise while spreading awareness at the same time. See page six for ways you can get involved.*

All of these components are integrated in our STEP UP Campaign, culminating with the year end CELEBRATE phase, honoring those currently battling scleroderma and remembering those patients who have lost their lives to this devastating disease.

You can make a difference!

Step Up, choose to join the cause, volunteer to help others, not allowing your scleroderma to define you and if you need support others are here to help. Remember you are not alone in this journey; family, friends, the foundation can brighten your day.

HAPPY HOLIDAYS and BEST WISHES for a HEALTHY 2020!



Bruce Cowan
Executive Director



Scleroderma Foundation Tri-State & Michigan Chapters Presents

Free Educational Webinar Series



Starting next year, we will feature presentations by scleroderma experts on a number of relevant topics in a new format with the educational webinar series.

Join the sessions from either your computer or phone. You will have the ability to ask questions in a live format.

Check www.scleroderma.org/tristate for updated times and dates in 2020!

The National Commission on Scleroderma and Fibrotic Diseases Act of 2019



On June 24, 2019, Congressman Peter King (R-NY-2) introduced H.R.3446 *The National Commission on Scleroderma and Fibrotic Diseases Act of 2019* along with 8 original co-sponsors. This bill will establish a National Commission on Fibrotic Diseases within the National Institutes of Health (NIH) to evaluate and make recommendations regarding improvements to the coordination and advancement of NIH-supported research activities related to fibrosis and fibrotic diseases, which may include scleroderma as a prototypical condition that can cause fibrosis in various organs. NIH is part of the federal government and is the world's foremost medical research entity. Annually, NIH supports research projects that advance scientific understanding of the mechanisms of various diseases, including scleroderma. Medical breakthroughs facilitated by NIH research are often what the industry uses to develop new therapies, cures and diagnostic tools.



How can you get involved?

The first step is to educate yourself by visiting www.scleroderma.org/advocacy. Once there, read the bills and see who has sponsored them. You can also download the letters that you and your loved ones can sign and pass along to your congressional representatives asking them to be a sponsor. Full instructions are available on the webpage. The next step is to organize a group visit to your congressman's local office. A group of scleroderma volunteers in Rochester did just that in August and within days congressman Joseph Morelle (D-NY-25) cosponsored the house bill, H.R.3446.

You can also be a strong advocate at the state level, as well as with county and city government officials. Meet with representatives and share your personal journey with scleroderma, raising awareness of your cause along the way. We can help with organizing a local visit, letters of introduction, and answering your questions. **This is a nationwide campaign, so please enlist your family and friends from around the country to advocate for your cause at all levels of government.**

Advocating for advancements in scleroderma research is not political, it's personal. Scleroderma impacts Republicans as well as Democrats, conservative folk and liberals alike, it can place a tremendous burden on the lives of patients, their families, and their caregivers. We need you to tell your personal story and join together to educate your elected officials.



On September 12, 2019, Senator Kirsten Gillibrand (D-NY) introduced Senate Bill S.2447, the senate's version

of *The National Commission on Scleroderma and Fibrotic Diseases Act of 2019*. These two bills have bipartisan support from Democrats and Republications. They are budget neutral – the bills will not increase federal spending and are not disease specific as all fibrotic diseases (including scleroderma) will benefit.

Capitol Hill Day for Scleroderma was Tuesday, September 17th. Fifty scleroderma volunteer advocates from around the country, *including seven from the Tri-State region*, traveled to Washington to call on their congressional representatives. They came from 22 different states and were able to conduct 75 meetings that day, telling their personal stories of why these bills are important to them.



Want to make a DIFFERENCE? Get your charitable gift MATCHED!



You made a donation towards the Scleroderma Foundation Tri-State Chapter, but what's next? **Did you know that many companies match donations made by their employees to our organization?** You can instantly double the impact of your initial donation by contacting your employer and inquiring about their matching gift program.

Every dollar counts and it is awesome matching gift programs like these that make a DIFFERENCE!

Ask your employer about Payroll Deduction!

Some companies will allow you to donate to the Scleroderma Foundation Tri-State Chapter through your employee workplace campaign!

Choose the appropriate number to support our cause:

- United Way choose Scleroderma Foundation/Tri-State Chapter IRS#13-3128296
- New Jersey Employees Charitable Campaign choose 6582
- State Employees Federated Appeal choose 999-00581
- Combined Municipal Campaign & CUNY choose 2539



Scleroderma Awareness Items *Rock Your TEAL!*



36"x36" Ladies SF Damask Pattern Scarf \$25 each

Navy Knit Hat \$18 each



Adult SF Shell Pattern Neck Tie \$25 each

Touchscreen Gloves \$8 each



Teal Scleroderma Earrings \$40 each



Embroidered Fleece Blanket \$25 each

Navy Hoodie \$25 each



Flashlight/Rechargeable Portable Power Bank \$5 each

Gel Hand Warmers \$5 a pair



Shipping cost as follows based on Merchandise Total:

\$5-30: \$5.00; \$31-100: \$10.00; \$100 or more: Free Shipping

To place an order, call (800) 867-0885!

Looking For Support?



Visit sclerodermatrystate.org for additional information.

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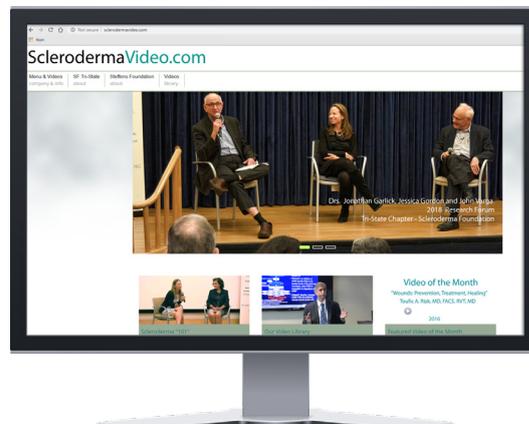
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Miss one of our Educational Forums?

Put on your fuzzy socks, grab a cup of tea and head to
SclerodermaVideo.com...

Tri-State films all education forum speakers and makes the videos available online. These videos were talks given by Physicians, Researchers and other experts in their fields in front of live audiences. If you want to learn more about a specific topic, you can see all the videos organized by subject. For example, if you are new to learning about scleroderma, you can head to the Scleroderma 101 section where there are videos hand-picked for newcomers. If you missed an educational event, search by event and discover topics covered.

There is a wealth of free information about scleroderma at SclerodermaVideo.com, available 24/7!



Make an IMPACT!

Ever considered taking a stand for something and representing a cause?

Join the hundreds of people that have *Stepped Out* and *Stepped Up* for Scleroderma this year through Peer-to-Peer Fundraising.

What is peer-to-peer fundraising?

Peer-to-peer fundraising is a way that you can interact with your network to encourage them to stand with you for a cause. Whether hosting a BBQ event where your attendees give donations or organizing a bake sale, consider hosting a peer-to-peer event to support the Tri-State chapter. Here are some events that have already been held in our region:



- *Scleroderma Summer Fair* held in Buffalo NY; organized by **Amanda Hebert & Debbie Golinski**
 - *Scleroderma Awareness Concert* held in Bronx, NY; organized by **Tameka Nelson**
 - *Newburgh Brewery Event* held in Newburgh, NY; organized by **Antonietta Chiochi**
 - *Jean Day* organized by **Visions Federal Credit Union**

And there are other events that help the Foundation as a whole such as Hope Raisers:

- Hope Raisers, organized through the National Foundation, helps fund research such as the *Jet Ski for Julia Hope Raiser*, which can be found in the *Scleroderma Voice* summer issue on pages 18-19

All these events helped our mission to educate and support people with scleroderma and their families, stimulate and support research, and enhance public awareness of this disease.

Can't host an event?

Consider an online fundraiser through **Facebook** or **GiveLively.org**.

- Facebook Fundraisers such as **Jennifer Levitt** and **Claudette Johnson** reached out to their social network to help raise funds for the Stepping Up to Cure Scleroderma walks

Want to setup a GiveLively.org Fundraiser? Contact our office for more details.



Are you an online streamer on Twitch, Facebook, YouTube or Mixer?
Consider doing a charity stream through **Tiltify.com**.

Consider making an **IMPACT** and continue to **STEP UP!**

Step Up for Scleroderma



Back in August, our Step Up Campaign launched on social media, inspiring people to fundraise, advocate, care and celebrate for those affected by scleroderma. Each step was designed to act as a supporting component to our three-fold mission to educate and support people with scleroderma and their families, stimulate and support research, and enhance public awareness of this disease.

But, have you Stepped Up for Scleroderma?

You might say, I participated in a Stepping Out to Cure Scleroderma walk in June, do I need to still Step Up? If you attended a walk, we would like to say thank you very much and challenge you to Step Up by sharing your walk page to help spread awareness of this awful disease.

What if I signed the advocacy letter and sent it into my representative? Thank you again. You have Stepped Up, but we empower you to check the advocacy page on how you can continue acting as a scleroderma advocate. But don't forget that you can also advocate for your loved one by acting as their health advocate.

How can I care? Struggling with scleroderma can be challenging for patients. If your loved one is affected by scleroderma, we inspire you to educate yourself with valuable resources found on sclerodermavideo.com and Inspire. As a patient or caregiver, joining a local support group is a great opportunity to create connections with other scleroderma warriors. We encourage you to Step Up and connect with the valuable resources through our website.

As we prepare for the end of the year, we would like to **CELEBRATE** with you. It is time to Step Up for Scleroderma, remember those currently battling scleroderma or those who have lost their battle.



For more information on how you can Step Up for Scleroderma, please find us at [Facebook.com/SclerodermaTS](https://www.facebook.com/SclerodermaTS), [Twitter @SclerodermaTS](https://twitter.com/SclerodermaTS), [Instagram @SclerodermaTS](https://www.instagram.com/SclerodermaTS) or our office for further details.

Stepping Out to Cure Scleroderma Walks



Every year, our Stepping Out to Cure Scleroderma walks are held in June with the help of volunteers throughout our region. **2020 will bring an opportunity for additional volunteers with the Syracuse walk.** If you are interested in volunteering for one of our walks, please contact the office for details.

2020 Stepping Out to Cure Scleroderma walk locations: Albany, NY; Binghamton, NY; Hartford, CT; Long Island, NY; Manhattan, NY; Poughkeepsie, NY; Ridgefield Park, NJ; Rochester, NY; Syracuse, NY; Westchester, NY.

Call 800-867-0885 - update your contact information and receive the latest Tri-State news.



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Please note your membership ends on the date provided in your address box.

The Scleroderma Foundation in no way endorses any of the drugs or treatments in this newsletter; the information is provided to keep readers informed. Because the manifestations and severity of scleroderma vary, individualized medical management is essential. Therefore, it is strongly recommended that all drugs and treatments be discussed with the reader's physician(s) to assure proper evaluation and treatment.

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City _____ State _____ Zip _____

One-Time Amount _____ or a Sustaining Monthly Amount _____

Checks payable to SF Tri-State (email required) or Donate online www.SclerodermaTriState.org

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Contribution is made: in honor of in memory of as a donation with membership

Membership: New Member Member Renewal No Membership

If New Member or Member Renewal is checked, the first \$25 of your donation will go towards your membership to both the Tri-State Chapter and National Scleroderma Foundation.

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No acknowledgement needed **Send acknowledgement to:**

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