



**Awareness. Diagnosis. Education. Research.**

**Our mission** is to support and promote research toward treatment and cure of Scleroderma, Degos Disease, and other related disorders, to promote awareness and understanding of these disorders, especially among health-care professionals, and to encourage collaborative efforts, nationally and internationally, aimed at realizing these goals.

## Expanding Medical Advisory Board



Dr. Lee Shapiro, Chief Medical Officer of the Steffens Foundation, has forged strong collaborative relationships with Scleroderma and Degos Disease experts nationally and internationally. He recently invited 3 physicians and a medical ethicist, who are prestigious experts in their fields, to join Steffens as members of the medical advisory board for the foundation. They all graciously agreed to join Steffens in our mission. It is with great pleasure, we introduce Dr. Lesley Saketkoo, Dr. Leslie Frech, Dr. Patrick Whelan, and Stephen Veit, medical ethicist.

**Dr. Lesley A Saketkoo, MD, MPH**, is a researcher, educator and clinician in scleroderma/systemic sclerosis, sarcoidosis, myositis, pulmonary hypertension and interstitial lung disease. In 2011, she established the Scleroderma and Sarcoidosis Patient Care and Research Center between Tulane and Louisiana State University, "center of excellence" by the European Scleroderma Trials and Research Group (EUSTAR), the Scleroderma Foundation, and the Scleroderma Clinical Trials Consortium (SCTC); and also established the Pulmonary Hypertension clinic program at LSU, which is now the LSU-Tulane collaborative Comprehensive Pulmonary Hypertension Center (CPHC) at University Medical Center, a Pulmonary Hypertension Association certified center of excellence.



In addition to clinical trials and registries in rare multi-organ system diseases, Dr. Saketkoo is dedicated to research that illuminates patient priorities and incorporates patients' expertise in clinical trial design, learning about the disease, along with how manifestations of the disease begin and evolve over time. Dr. Saketkoo has been dedicated to wellness education that empowers patients living with chronic illness for biological and psychosocial wellness. She is a founder of G-ForSS, the Global Fellowship on Rehabilitation and Exercise in Systemic Sclerosis, which is group of PTs, OTs, physicians, and basic scientists dedicated to defining exercise and physical activity's medicinal impact on systemic inflammation, fibrosis, functional ability and psychosocial ease in SSc. Dr. Saketkoo was named Doctor of the Year in 2018 by the Scleroderma Foundation.

## Dr. Tracy M Frech



She trained at the University of Utah for internal medicine and pediatrics residency, adult rheumatology fellowship, and a holds an MS in clinical investigation. Dr. Frech's primary goal in research and clinical care is early diagnosis and effective health care delivery to the systemic sclerosis (SSc) population. Her specific research interest is to better understand the natural history of symptomatic vasculopathy in SSc. To that end, through collaborations with Prospective Registry of Early SSc (PRESS), the INception SYstemic Sclerosis Cohort (INSYNC), the Collaborative Quality and Efficacy National Registry (CONQUER) for SSc, and the Utah Vascular Research Laboratory (UVRL). Her academic career focuses on improvements in diagnosis and treatment of SSc through meticulous patient

**Thank you to all who attended our Cruise for a Real Cure!**

**More than 100 people took a ride along the Hudson River on the Dutch Apple to raise awareness and funding for Scleroderma and Degos Disease research and education.**



**Thank you to all who donated to make the event a success!**

- Dutch Apple Cruises & Tours
- DeMarco's Italian-American Restaurant
- Ellms Family Farms
- USS Slater
- Tri-City Valley Cats
- Fred Astaire Dance Studio
- 1<sup>st</sup> National Bank
- Sweet Willey's
- Snowman's Ice Cream
- Oriental Trading Company
- Casa Visco
- CVS
- Advance Auto Parts
- Parkway Liquor

### Annual Fall Event – October 23, 2021

The event will be held at **River Stone Manor, 1437 Amsterdam Rd, Schenectady, NY 12302.**

To receive an invitation, email: [cmarceline@steffens-scleroderma.org](mailto:cmarceline@steffens-scleroderma.org)  
More details to come [Click Here.](#)

**Welcome New Board Members:**  
**Mark Slayton & Christine Marceline**

**Donate Online:**  
[steffens-scleroderma.org](http://steffens-scleroderma.org)

phenotyping. Dr. Frech's 15 year tenure as Director of the University of Utah SSc Clinic, principal investigator of multiple clinical trials, participation in several international collaborative efforts, has identified the importance of outcome definitions and data standardization for effectively monitoring and treating SSc patients. Dr. Frech is currently seeing SSc patients at Vanderbilt University, her primary academic appointment. She also serves as an adjunct associate professor at the University of Utah. She presents her research at national and international scientific meetings as well as at patient outreach conferences. She is passionate about clinical and translational research in SSc, and believes precision medicine techniques hold promise for discovery in SSc. Dr. Frech is dedicated to teaching medical students, residents, and fellows in clinic, as well as through their research projects. Her aim is to develop the next generation of academic rheumatologists committed to clinical and research excellence and compassionate health care delivery. [Dr Tracy Frech 2020 Physician of the Year](#)

**Dr. John Patrick Whelan**, MD Ph.D. is an Associate Clinical Professor of Pediatrics in the Division of Rheumatology at UCLA. He completed his undergraduate degree in biochemistry at Harvard University, the Ph.D. degree at Texas Children's Hospital in Houston, and the MD degree at Baylor College of Medicine. He completed rheumatology training at Harvard and was for twenty years a pediatric rheumatologist at Massachusetts General Hospital in Boston. His research interests pertain to non-inflammatory vasculopathies, particularly Kohlmeier-Degos disease.



Dr. Shapiro's and Dr. Whelan's joint efforts began over a decade ago when Dr. Shapiro consulted Dr. Whelan regarding a critically ill pediatric Degos patient. One result of this collaboration has been the development an international Degos Disease study group.

**Stephen Veit** has worked at Albany Medical Center for the past 19 years in the Pathology department. He holds the position of Technical Specialist and is a national and state certified Histotechnologist. His position at the hospital requires some responsibility regarding management of the laboratory. While in this position, Stephen continues to work towards finishing his doctorate in Medical Ethics. Dr. Shapiro established a working relationship with Stephen Veit as a result of their professional paths crossing at Albany Medical Center.

**Steffens also Welcomes - Steve Rosenblum** joined the Steffens Foundation in the role of Project Manager in May 2021. Steve established a "Core Team" to focus on the dissemination of information regarding the highly successful Interprofessional Education program in hopes of inspiring replication of the program elsewhere. The team recently presented at the National Scleroderma Foundation's annual conference (see margin), and assisted in the submission of a large grant. The team's upcoming focus will be the creation of an eBook "How-To" Guide to Planning and Hosting a Scleroderma IPE with the goal of identifying and mentoring one or more new pilot IPE programs in the coming year.

Steve comes with extensive experience in project management and event planning, and has proven himself invaluable in moving our recent projects forward in a timely and efficient manner.

### Steffens Presents at National Conference

The Steffens Scleroderma Foundation and partners from Russell Sage College and Albany College of Pharmacy and Health Sciences developed and presented on the unique and collaborative scleroderma focused Inter-professional Education (IPE) annual event and model at the **National Scleroderma Foundation Patient Education Conference** that took place July 17-18th. Under the leadership of Project Manager Steve Rosenblum, a poster and live-presentation was prepared by a core team of those involved in the planning and execution of the IPE event each year. The goal for the presentations was to share the model with the public in hopes that this novel approach to inter-professional education; which highlights patients as experts and educators about their disease process and experiences, can be replicated across Scleroderma Centers nationwide. Several benefits have been identified as result of this educational model to include, patient advocacy and empowerment and increased education and awareness of scleroderma among future healthcare professionals.

### More National Recognition:

Dr. Jeffrey Brewer, Director of Professional Affairs and Assoc. Professor of Pharmacy Practice at the Albany College of Pharmacy and Health Sciences, presented the IPE Model at the 2021 Interprofessional Leadership Development Program (ILDP). Full story [click here](#).