



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.

What is Scleroderma?

Scleroderma is a rare disease that leads to fibrosis or hardening of the skin and connective tissue. The disease varies from person to person in terms of extent, its patterns of skin and organ involvement, and the rate of progression. It can also affect the lungs, kidneys, heart and other internal organs. In the U.S., approximately 100,000 people have scleroderma.

What is Degos Disease?

Degos disease is an ultra-rare vascular disease presenting as skin lesions (porcelain plaques) that appear, at first, small, raised, red-rimmed (erythematous, telangiectatic rim) with a white center and over time, flattened and depressed. Degos disease has two forms; Cutaneous (skin only) lesions and Systemic lesions that occur most commonly in the gastrointestinal (GI) tract and central nervous system, but also can occur in the brain, pericardium (membrane around the heart), bladder, and eye. Approximately 1/3 of patients eventually progress to systemic disease. Untreated systemic Degos disease may result in GI perforations, sepsis, damage to the lining around the lungs (pleura), and strokes.

No Cure There is presently no cure for either disease, but proper treatment can reduce symptoms and damage from the diseases. For more information visit our website.



Lee Shapiro, MD Chief Medical Officer and Executive Committee Member

Dr. Lee Shapiro, a prominent rheumatologist, plays a leading role in the foundation as its Chief Medical Officer and as an Executive Committee Member. Dr. Shapiro is a professor at Albany Medical College, as well as an active researcher. His research focuses on vascular aspects of scleroderma, Degos disease, calcinosis and related disorders. His practice site is the Scleroderma Center, Albany Med,

Division of Rheumatology in Malta, New York.

Dr. Shapiro has been honored for his tireless advocacy and compassionate treatment of patients affected by scleroderma and Degos disease. His accolades include being named the Scleroderma Foundation Doctor of the Year, receiving the Distinguished Physician Lifetime Achievement Award in 2007 by the Scleroderma Foundation, and being inducted into the CDPHP Physicians Academy, which recognizes physicians who serve as role models to their medical colleagues and who act as ambassadors in fostering the delivery of high-value health care.

The Steffens Scleroderma Foundation's 2020 Virtual Cruise for a Cure was a huge success! More than 100 people took a virtual ride along the Hudson River, including U.S. Congressman Paul Tonko and Dr. Lee Shapiro, to raise awareness and funding for Scleroderma and Degos Disease research and education. Thank you to all who participated!!



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Research



Dr. Shapiro is currently working with a third-year Albany Medical College student, Samantha Sattler, on a review of gastrointestinal manifestations of Degos disease. An abstract based on this work was accepted for a poster presentation at this year's (virtual) meeting of the American College of Gastroenterology. The goal of this project is to provide information to patients and providers on

aspects of gastrointestinal Degos, including pathology, demographics, the diagnostic process, bowel visualization, complications, and current treatments. They also hope to interview patients living with gastrointestinal Degos to learn more about symptoms at disease onset, daily challenges, lifestyle changes, and personal insights that may not be apparent to physicians and other care providers.



Dr. Shapiro and Samantha have more recently begun a project focused on laparoscopic imaging of gastrointestinal Scleroderma. There is a current gap in medical knowledge regarding the appearance and pathology of scleroderma bowel disease. Working with Dr. Frech of the University of Utah School of Medicine, the team hopes to develop a protocol which could be employed at the time of elective laparoscopic surgeries to further characterize the disease process.

How are you really doing?

Dr. Lee Shapiro, scleroderma specialist, and a team of researchers are interested in what people with systemic sclerosis (scleroderma) have been going through during the COVID-19 pandemic. Is this pandemic affecting your healthcare? How are you coping with the risk of COVID-19? How do you feel about the uncertainty that the pandemic can bring to people's lives? How are you feeling physically and mentally? The more we understand about the experience of people with scleroderma during the COVID-19 pandemic, the better able we are to help people stay well.

If you are interested in finding out more about this study, please go to:

<https://www.surveymonkey.com/r/COVID-Scleroderma3>

This link will give you more information about the study, including how you can participate. People who participate are able to choose to be entered in a random drawing of four \$25 Amazon gift cards.



Upcoming Events:

**October 10, 2020 -
Stepping out to Cure Scleroderma
SteppingOutWalk.org**

**November 14, 2020:
4th Annual Fundraising Gala
Riverstone Manor, Scotia, NY**

**Spring 2021:
Interprofessional Education IPE**

**We had a successful Virtual Painting
with a Twist that included about 40
painters. Thank you to all who
participated.**



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