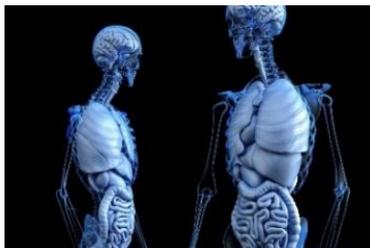




Our mission is to support and promote research toward treatment and cure of Scleroderma, Degos Disease, and other related disorders, to promote awareness and understanding of these disorders, especially among health-care professionals, and to encourage collaborative efforts, nationally and internationally,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

Current Projects ongoing in 2021

Steffens Scleroderma Research Foundation is committed to increase awareness of Scleroderma and Degos Disease among healthcare professionals through our annual Interprofessional Education Event (IPE). Initiated in March of 2018, it has included hundreds of healthcare professional students from local academic institutions. In March of 2021 a fourth IPE is planned, this year on a virtual platform due to COVID-19.



We have current research collaborations with Albany Medical College, Albany College of Pharmacy and Health Sciences, Russell Sage Colleges, College of St. Rose, and most recently, the School of BioMedical Engineering at Rensselaer Polytechnic Institute.

With all the ensuing 2021 projects, we are delighted to welcome Hannah Bowen, a much needed research assistant, to our team. Ms. Bowen is working in direct support of Dr. Shapiro. In addition, she is currently working on her masters in Translational Biomedical Research, and is researching treatment for the COVID-19 virus.

Other professionals involved with Steffens in 2021 are Patricia Fennell, MSW, LCSW-R, of Albany Health Management Associates, Inc and Nancy Dorr, PhD, Professor of Psychology at the College of Saint Rose. Along with Dr. Lee Shapiro, they conducted a study examining how the COVID-19 pandemic may be affecting the health and wellness of people with Scleroderma. Please go to www.albanyhealthmanagement.com for further information and resources.

Dr. Swati Mehta, Associate Professor at Albany Medical College, is currently researching late onset renal crisis in Scleroderma. She and Dr Shapiro are studying patients that develop renal crisis within the initial five years of having Scleroderma, and those that develop renal crisis after five years with the disease. The goal is to study differences in clinical characteristics, outcomes, and overall mortality from this complication. In addition, potential correlation of socio-demographics, race, and ethnicity will be evaluated and explored. This is a large multicenter research endeavor. Dr. Robyn Domsic of UPMC & University of Pittsburgh, Arthritis and Autoimmunity Center, Dr. Laura Hummers of Johns Hopkins Scleroderma Center, and Dr. Virginia Steen of Georgetown University Hospital, along with medical students are all participants in the research.

Dr. Patrick Whelan is a Pediatric Rheumatologist at UCLA who collaborates with Dr. Shapiro on Degos research. He encountered his first pediatric Degos patient in 2005, writing about his experiences in the New England Journal of Medicine that same year. This experience led to his continued treatment, research, and advocacy for awareness of Degos Disease in the medical community. He personally met with Ernie DuPont, Jr. and his parents, Ernie and Sue DuPont, to better understand the effects of the progression of this disease in the pediatric population. Dr. Whelan has observed the occurrence of strokes in the pediatric Degos Disease population, and is currently studying this complication. Dr. Whelan has also noted significant similarities between vascular disease in COVID-19 and vascular pathology seen in



Steffens Scleroderma Foundation's 2020 Virtual Gala fundraiser: Evening of Comedy and Connection
It was a great evening of information, comedy by Carole Deyoe and music by Robert Buckley. Congratulations to Amy Gietzen, the Ernie J. DuPont Award recipient and Bruce Cowan, the Louis P. Renna Award. Thank you to all who participated!!



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Degos patients. At a recent conference of medical professionals, Dr Whalen encouraged his colleagues to look at this similarity, “Degos disease can be a window into what is happening in COVID, and COVID can be a window into what is happening with Degos.” For more information about Ernie DuPont’s battle with Degos Disease, visit our website,

www.steffens-scleroderma.org/conditions/patient-stories

“Our focus is on Scleroderma and Degos Disease. Both have small vessel changes that lead to many of the effects of these diseases. In Scleroderma, we look at the vascular aspects of the disease in particular research into kidney disease, into calcinosis (calcium deposition) and gastro-intestinal Scleroderma, which we believe and are trying to prove is related to vascular changes. For Degos Disease, we are trying to fill a void by developing effective means for quickly diagnosing, of treating and obtaining access to treatment for the disease,” Dr. Lee Shapiro. We have become a leader in Scleroderma focused Interprofessional Education, which has raised awareness of the disease. We have become the global beacon of hope for individuals with Degos disease.

COVID-19 Vaccine

Individuals with Scleroderma and Degos Disease may feel the stress of COVID-19 even more acutely than others. The Scleroderma Foundation and American College of Rheumatology have updated information in regards to the vaccine which can be found on their websites. Please contact your physician for specific information pertaining to you.

www.scleroderma.org & <https://www.rheumatology.org/announcements>



Student Research



After attending the 2019 annual IPE event, a group of 4 Russell Sage College Occupational Therapy graduate students realized there was a lack of OT research addressing splinting of the Scleroderma hand. The last publication they found on the subject was from 1987. They are currently conducting a pilot study on a splint fabrication process that may slow down the progression of hand contractures often

affiliated with Diffuse Scleroderma. The past clinical problem has been poor tolerance of corrective splinting in the Scleroderma hand, permitting deforming forces to go unchecked. This often results in pain and loss of function for the person over time. The Sage students collaborated with PVA, a 3D printing company in Cohoes, NY, and Steffens. Study methods were modified due to restrictions in place for COVID-19. PVA printed models of forearms and hands from 4 healthy subjects. Celeste Freeman, OTR/L, CHT, fabricated custom resting splints on the 3D models. Fit and comfort of 4 different materials will be assessed by the subjects. The goal of this pilot study is to determine the most comfortable material for overnight wear and to determine methods for splinting on the 3D models of forearms and hands, thus reducing splint fabrication risk to individuals with Scleroderma. The intent is to use this data for the next phase of research, applied to individuals with Scleroderma, once COVID-19 restrictions are lifted.

Upcoming Events: Spring 2021: Interprofessional Education IPE

Congratulations to Carla Gage, the new President of the foundation.

Thank you, Ernie DuPont, for your hard work and dedication to the foundation. Ernie was an original member of the board and the first President. The board extends its deepest gratitude for his accomplishments and extensive hours he gave to achieve Steffens Foundation goals from the first meeting held in 2011 to 2020. His leadership style was inclusive and democratic. He gave our budding foundation wings to grow and move forward.

Farewell from Jenny Sparano:

“It’s been my pleasure to support the work of the foundation and get to know the talented volunteers on the Board. The new website is a great tool for educating people around the world about scleroderma and Degos disease, and promoting the mission to advance research to find better treatments and, someday, a cure. I got involved because I was inspired by the stories of patients in the community and the unwavering commitment of Dr. Shapiro. I will continue to help where I can and will always be rooting for this very special group of friends who are doing extraordinary work for others.”

Jenny Sparano led the creation of the new website, revitalized the newsletter, established the content pillars and was a vital member of the Steffens Foundation board.

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