

4th Annual Interprofessional Education Conference



Focus on Scleroderma

In an ongoing effort to promote awareness and understanding of scleroderma, the Steffens Scleroderma Foundation held its 4th annual Interprofessional Education (IPE) Forum on March 24, 2021. The virtual event used Zoom to connect 238 professionals, students and patients, who participated from the comfort of their homes, offices and dorms.

The IPE involved students from five health professional schools at Russell Sage College (occupational therapy, physical therapy, nursing, nutrition and psychology), SUNY Albany's School of Public Health, and the Albany College of Pharmacy, for a total of about 200 students. The IPE introduces students in the health sciences to Scleroderma with the objective that future health care professionals are better informed about this rare and complex autoimmune disease.

Groups of students from each professional discipline were paired with individuals diagnosed with Scleroderma, and some caregivers of loved ones with Scleroderma. The students were assigned learning objectives regarding Scleroderma prior to the event. There were multiple speakers as well as small group discussions held in breakout rooms. In this more personal format, patients and caregivers shared their stories about the journey toward diagnosis, and the challenges of living with this difficult disease. The students were then invited to ask questions of the patients in order to better understand the patient's needs and the potential role of each discipline in the treatment and management of Scleroderma.



Amy Gietzen, a patient advocate and motivational speaker was diagnosed with scleroderma at age 19. Ms. Gietzen was the keynote speaker for the IPE this year. She discussed the challenges and successes of living with a rare autoimmune disease for more than two decades. During the summer of 2020, she had complications from her illness and was hospitalized. Unfortunately, as is common with Scleroderma, she found herself being treated by staff who were unfamiliar with her disease. Unable to have family with her due to Covid restrictions, she expressed the feeling of vulnerability and loneliness. Out of fear of being mismanaged, she stayed awake for several days in order to ensure the staff understood her diagnosis and avoided medical errors. This powerfully illustrated the objective of the IPE to the attendees. Later in the event, students had the opportunity to question Amy about her experiences.



Carla Gage our new President of the Steffens Scleroderma Foundation.

Carla studied at the State University of NY and Vanderbilt University ABA Bank Operations. She obtained certification as a Treasury Professional with the Association of Financial Professionals.

Carla retired from Bank of America as a Senior Vice President in Operations. She was diagnosed with Scleroderma in 2012. Carla joined the Capital District Support Group for scleroderma patients. "Subsequently, I became the Group Leader and a board member of the Scleroderma Tri State Chapter," she says. "I became involved with the Steffens Foundation because of my passion to not only help other patients, but primarily to educate those in the health profession about this extremely rare disease."

Previous IPE Forums are available for viewing via a link on www.steffens-scleroderma.org/

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The event also featured an Expert Panel from diverse specialties. They answered questions from student participants. Questions from the students for patient participants as well as the Expert Panel were critiqued by Heather Frenz, coordinator of the Patient Simulation Program at Albany Medical College and a person with Scleroderma herself. Feedback from students,

participants with Scleroderma, and their caregivers, has been extremely positive. The success of the IPE is a result of a growing partnership between the Steffens Scleroderma Foundation, Russell Sage College, Albany College of Pharmacy and Health Sciences, SUNY Albany's School of Public Health and Dr. Lee Shapiro's Scleroderma Center at Albany Medical College. The ultimate goal of the IPE is to raise awareness amongst entry level health care professionals at a clinical level. The hope is that this will contribute to the reducing the length of time from onset of early symptoms, to accurate diagnosis and effective disease management for people with Scleroderma. The Steffens Scleroderma Foundation continues to be a driving force in promoting awareness and understanding of Scleroderma among health care professionals as well as promoting research. We thank everyone for their participation and making this event a success.

There has been much activity this quarter in the area of research and projects regarding both Scleroderma and Degos Disease. The Steffens Scleroderma Foundation will present the IPE as a model at the national Scleroderma Foundation Annual Meeting in July 2021 to demonstrate the role of individuals with Scleroderma as educators to health care providers. Additionally, a poster presentation will be submitted on the subject.

Scleroderma Updates

Publications

Dr. Lee Shapiro is a contributor to two papers submitted for publication. The lead author is Dr. Leslie Saketkoo, MD, Tulane University Scleroderma Center, with whom Dr. Shapiro has collaborated on multiple projects. The first paper is titled, "Exercise as a Multi-Modal Disease Modifying Medicine in Systemic Sclerosis". The second paper is titled, "Framework for Navigating Patient Care and Patient Visits in Systemic Sclerosis".

RPI Collaboration

There has been a fruitful collaboration with RPI biomedical engineering students this past semester. Dr. Shapiro and Celeste Freeman were mentors/advisors to two groups for their capstone design projects. One group designed hand warming gloves for people with Scleroderma/Raynaud's phenomenon, that would provide heat to hands but minimize loss of dexterity, "Dexterous Hand Warming System". The second group undertook development of a product called "Oxy Digit", a portable hyperbaric system to provide concentrated oxygen to hands with ulcers from reduced blood flow seen in Scleroderma. Each group produced a physical prototype of their design. In addition to mentoring, Steffens Foundation provided funds for the materials needed for the prototypes.



College of St. Rose, Steffens Scleroderma Foundation, Albany Health Management Collaboration

Four abstract presentations that were given last year, on "Path to Diagnosis", and "Trauma Associated with Scleroderma Diagnosis" are currently being developed into a manuscript for publication. Another venture by the group this year was data collection to study the "Impact of Covid-19 Pandemic on Health and Healthcare of Individuals with Scleroderma". Approximately seventy patients participated in the data collection, all from the Albany Medical Center (AMC) Scleroderma Clinic.



Albany Medical College Collaborations

Dr. Lee Shapiro co-authored a journal article addressing swallowing difficulties in Scleroderma with AMC gastroenterologist Dr. Michael Tadros and five Albany Medical College students.

Dr. Shapiro is to be co-editor with Dr. Tadros and a third physician for a textbook on gastrointestinal manifestations in Scleroderma.

Another joint venture is a project addressing “Late Onset Scleroderma Renal Crisis”. This is in cooperation with Scleroderma centers at AMC, Johns Hopkins, Pittsburgh, and Georgetown. Data collection is currently underway, and a grant is being sought from the Scleroderma Clinical Trial Consortium, (SCTC), to support the project.

Also at AMC, a medical resident, Dr. Mario Felix, is developing a project examining healthcare disparities in diagnosis and treatment of Scleroderma.

Albany College of Pharmacy and Health Sciences (ACPHS) Collaboration

Dr. Jessica Farrell has identified three ACPHS students interested in engaging in Scleroderma related pharmaceutical research. Weekly meetings with the students, Dr. Shapiro, and Dr. Farrell have been established to develop projects ideas.

Dr. Farrell and Dr. Shapiro co-authored, in conjunction with a pulmonologist at the University of Washington, reviewing drug therapy for interstitial lung disease.

Degos Disease Updates

Samantha Sattler, Albany Medical College, 2022, has had an abstract accepted for presentation at the American Academy of Dermatology, and has also submitted an abstract on “Ophthalmologic Presentations of Degos”, to the American Academy of Ophthalmology.

Dr. Shapiro is preparing review papers with Ms. Sattler at AMC on gastrointestinal and ophthalmologic manifestations of Degos Disease.

Dr. Shapiro has co-authored a paper with a group of dermatologists at the University of Toronto, on *predictors* of systemic involvement in individuals with cutaneous Degos Disease. The open publication of this was funded by the Steffens Foundation.



Dr. Shapiro and colleagues are preparing a “Manual on Diagnosis, Evaluation, and Treatment of Degos Disease” with the goal to have it available on the Degosdisease.com website.

Dr. Shapiro has organized an international working group on Degos Disease, and chairs monthly meetings of participants. Membership expansion is being promoted so that greater global coverage is achieved for this ultra-rare disease. Currently there is one participant from Russia, one from Germany, one from Iran, three from National Institute of Health, (NIH), one from UCLA, and one from California State University at Long Beach, (CSULB). The group is focusing on issues centered around drug access for existing therapies, and trial design for future therapies. There is a project underway to identify a therapeutic agent that might prevent progression from skin only to systemic disease. Another goal is identifying treatment that would arrest currently untreatable central nervous system Degos Disease.

Theresa Slayton, Board Member, Degos Disease Patient



The road to Steffens Scleroderma Foundation, adb as Degos Disease Research Foundation

Almost ten years ago, I awoke to an inflamed sore on my right thigh. Within weeks, there were many more on my limbs and torso. My Dermatologist, at that time, could not give me a definitive diagnosis for these lesions. I searched the internet for skin lesions with a white center and red surrounding. Devastating stories of Degos disease fatalities popped up. After about two years of investigation it appeared that the disease was only effecting my skin. Being

an RN helped me to understand that, even though this was life-altering, I believed it was not going to kill me. One year later, when I was hospitalized with severe abdominal pain, nausea and vomiting, I explained to the gastroenterologist that it could be an internal type of Degos that also effected my skin. He listened but did not indicate that he was familiar with the diagnosis. He did try to further visualize my gastrointestinal tract but did not see anything that would cause my symptoms. My abdominal symptoms became more acute, but finding a doctor to treat me became very bleak.

Thanks to the support of my family, I did not give up. I was able to find Dr. Lee Shapiro of Albany, NY, a Rheumatologist and expert in the treatment of Malignant Atrophic Papulosis (MAP), the clinical term for Degos disease. Dr. Shapiro started an immediate and resolute campaign that put me on a path to an accurate diagnosis of Systemic Degos disease and an effective treatment plan.

In an effort to ensure the same treatment and outcomes to those who develop Degos lesions, I modernized and began maintaining the Degos Disease Support Network website. Dr Shapiro introduced me to fellow survivors and involved me in the Steffens Scleroderma Foundation. I was led to the doorstep of the Steffens Foundation and was accepted with open arms. My goal as a Steffens board member, is to help all Degos patients and their physicians discover the Steffens Foundations where education, advocacy, and awareness flourish. The foundation aspires to share and centralize knowledge so that standards of care for MAP can be established within the global medical community.

It is now going on ten years since that first lesion appeared. In that time, many Degos patients have been diagnosed and Dr. Shapiro and the Steffens Foundation have advocated for each and everyone of them so that they have a fighting chance for survival.

Amy Gietzen, New Board Member

Amy Gietzen has been elected as a new board member for the foundation. Amy has been our key note speaker for the IPE and recently received the Ernie DuPont award at our Fall Fundraiser. She also serves on the board of the Scleroderma Foundation Tri-State Chapter board and on the Patient Advisory Board for SPIN (The Scleroderma Patient-centered Intervention Network). While Amy struggles every day, she has found a way to turn the negative into a positive by sharing her story and being an advocate for the scleroderma community.



Upcoming Events:

July 2021:

Cruise for a Cure:



We are Back on the Boat!!

Save the date for the 2021 Cruise for a Cure—Saturday, July 17th! We hope you'll mark your calendar and plan to join us as we raise awareness and funds to fight scleroderma and Degos disease. To celebrate being back on the boat, we are having a Mardi Gras themed cruise. So grab a fun mask and a hat, and join us on the river.

October 2021: Fall Fundraiser

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