

JUNE IS SCLERODERMA AWARENESS MONTH

In honor of June as Scleroderma Awareness Month, the Steffens Board is Pleased to Announce: Proclamation from the NYS Assembly for Scleroderma Awareness

K 615
New York Assembly
Resolution 2023 Regular
Session
Introduced in Assembly
Passed Assembly Jun 05,
2023
Senate
Governor



Memorializing Governor Kathy Hochul to proclaim June 2023, as Scleroderma Awareness Month in the State of New York

Dr. Lee Shapiro, was given the Proclamation by Assemblywoman Patricia Fahy, who introduced the bill, on June 5th, 2023 at the NYS Capitol. Those present for the event were, Assemblyman John McDonald, Pradeepa Jayachandran, PHD, ACPHS,



Dr. Micheal Tadros, AMC, Jessica Farrell, PharmD, ACPHS, Associate Medical Advisor Steffens Foundation, Donna Langan, Steffens Foundation board member, Assemblywoman Patricia Fahy, Dr. Lee Shapiro, Chief Medical Officer Steffens Foundation, AMC, Jeffrey Brewer, PharmD, ACPHS. They were accompanied by Larabe Farrukh, AMC, Medical Resident, Kara Olstad, PharmD, ACPHS

Ambulatory Care Pharmacy Resident, as well as Zachary Ahearn, Elizabeth Gambacorta, Alex Nolin, Sadie Lozier, PharmD candidates 2024 from ACPHS. We are thankful to Assemblywoman Patricia Fahy, and Assemblyman John McDonald for their support.

Annual Scleroderma IPE April 12th, 2023

The Ann Steffens Scleroderma Foundation, in partnership with Albany College of Pharmacy and Health Sciences, and Russell Sage Colleges, held the 5th IPE (Interprofessional Education) Event April 12, 2023. The event seeks to create an

Awareness. Diagnosis. Education. Research.

[PURCHASE TICKETS HERE](#)

Newest Medical Advisor to join The Steffens Foundation

David Leader, DMD/MPH, is an associate professor of comprehensive care at Tufts University School of Dental Medicine. He is the director of the emergency dental clinic and the DMD/MPH dual degree program. He is a member of the Scleroderma Foundation's Medical and Scientific Advisory Committee and a consultant for the Scleroderma Patient Intervention Network (SPIN). Dr. Leader received the Scleroderma Foundation Doctor of the Year Award in 2008 and has been a regular speaker for the National Scleroderma Foundation and Regional Chapters since 2005.

atmosphere to educate students of differing medical professions on the disease and diagnosis of scleroderma through both presentation and patient contact. The IPE was attended by close to 200 students representing dentistry, medicine, nursing, nutrition, occupational therapy, physical therapy, pharmacy, psychology/social work, and public health. Students from Albany College of Pharmacy, Russell Sage Colleges, Albany Medical College, The University at Albany, Tufts University, and Upstate Medical College participated. The keynote speaker was Amy Geitzen, a patient advocate and member of Steffens' Board of Directors. Amy shared her journey with Scleroderma, as well as the importance of having a team of medical professionals to provide optimal integrated healthcare for Scleroderma. Heather Frenz, Executive Director of the Patient Safety & Clinical Competency Center at Albany Medical College, demonstrated the art of active listening during a patient interview with Ms. Geitzen. A group of expert panelists were available to discuss the role of their respective disciplines with Scleroderma, and field questions submitted by student participants. Highlighting the evening was the opportunity for small groups of interdisciplinary students to interview a person with Scleroderma or a caregiver. These sessions provided the opportunity for direct application of the focus of the event. Several observers also attended, including a representative from our sponsor, Kaba Fusion, members of the Steffens Board of Directors, Tufts University, the University of South Carolina, and Florida International University. These universities have expressed an interest in replicating our IPE.

Thanks to our moderators: Jeffrey Brewer, Pharm D., Associate Professor of Family Medicine, Albany College of Pharmacy and Health Sciences, Alicia Harlow, PhD, Chair, Psychology Department, and Graduate Program Director at Russell Sage College, and Heather Bowen, Research Assistant, Steffens Scleroderma Foundation. Hannah Bowen is currently compiling the results of surveys completed by students and patients who attended the IPE. We look forward to sharing these results in the future on our website.

A Letter from our Chief Medical Officer, Dr. Lee Shapiro **Degos Disease and the Steffens Foundation, Questions and Answers**

What is Degos Disease? Degos Disease, also known as Atrophic Papulos or Kohlmeier-Degos disease is an "ultra-rare" disorder which can exist in a benign, (skin only), or in a systemic form. The disorder almost always presents with skin lesions with a very distinct appearance, a porcelain-white center with a red rim consisting of clusters of blood vessels. Roughly 1/3 of patients will go on to develop the systemic form of the disease. This form affects one or more body organs, most commonly the gastrointestinal tract or brain. Complications can include bowel perforation and a variety of neurologic and visual symptoms. If the skin lesions are not noted, diagnostic confusion is common, treatment may be delayed or improper, and for those with systemic disease, death from catastrophic complications may quickly occur.



DEGOS DISEASE

Current Scleroderma Research & Endeavors

Student Research Corey Fellon
M.D. Candidate, Class of 2026,
AMC

- Corey Fellon is pursuing research on the "Psychological Aspect of the Lip in Scleroderma" by building and facilitating a focus group of dermatologists and dermatology candidates.
- Corey Fellon and Hannah Bowen have submitted an abstract on the annual IPE to the American College of Rheumatology Convergence Conference.
- Corey Fellon and Hannah Bowen are currently developing a paper on the IPE for publication.

Why is the Steffens Foundation Involved?

Scleroderma and Degos Disease are separate entities, but there are shared pathologic features. In each disease there is damage to small blood vessels and impaired ability to repair the damage. Degos Disease can involve the lining of the heart and lung, and the changes there of fibrosis closely resemble the pathology of Scleroderma.

What has Steffens done?

Members of our advisory board, (Drs. Whelan, Farrell, and Shapiro), have long been involved in identifying new treatments for this disorder and promoting disease awareness so that earlier diagnosis can occur. They are committed to developing means of more rapid diagnosis of the systemic form of the disease in individuals with skin involvement. In 2018, the Steffens Foundation co-sponsored the first International Symposium on Degos Disease at the National Institutes of Health. In addition, the foundation provided financial support for the meeting, as Drs. Whelan and Shapiro were on the organizing committee. In more recent years, we continue close collaboration with the Degos team at the NIH. Drs. Whelan and Shapiro have organized international virtual meetings on Degos Disease which occur quarterly, attended by nearly all researchers involved in the investigation of this disorder. Dr. Farrell has become a resource for physicians throughout the world in providing details on the latest treatment, and navigating the enormous challenge of urgently obtaining the medications needed. Dr. Farrell presented, "Clinical Pearls & Approach to Treatments", to the online international meeting on Degos in June, 2023.

Presentations have been made at international meetings of rheumatologists, gastroenterologists, and dermatologists. An Albany Medical College student, Samantha Sattler, was lead author on the definitive review of gastrointestinal Degos Disease. The Foundation has provided support for research presentations on Degos by medical and pharmacy students, as well as Steffens research assistant Hannah Bowen.

Drs. Whelan and Shapiro are coauthoring a chapter on Degos Disease for the electronic medical text "UpToDate". Dr. Shapiro and Dr. Cynthia Magro, (Dr. Magro is the world's expert on the pathology of Degos), have coauthored a chapter on Degos which should appear in a textbook on vasculitis in 2024. Additionally, the team is currently at work on a review of "Long term survivors of Degos Disease".

The Degos Disease website is an international information resource and networking site for physicians, researchers, patients, and families and is administered and updated by Steffens Board member Theresa Slayton. This is invaluable to those seeking critical help with this disease. In recent weeks we have received inquiries from England, Germany, California, Michigan, and Colorado. Please visit the site <https://degosdisease.org/>.

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