

THE LEGACY OF THE MEENANS

From the CMO, an appreciation:

Peter and Linda Meenan recently stepped down from the board of the Steffens Foundation.

They were two of the original board members when the foundation was created in 2010 and served longer than any others.

Each took on leadership roles, Peter as chairman of the grants committee, Linda as chairman of the education and awareness committee (EAC), and vice-president of the foundation board.



Before joining the Steffens board, each had a long and distinguished career.

Peter was the manager of an advanced visualization and imaging research at GE Global Research Center. He brought his skills of critical thinking, team building, and establishing goals and strategies to our board.

Linda was an award-winning innovative educator. To Steffens, she brought extraordinary attention to detail, a passion for teaching, clarity of thought, and the ability to not only generate great ideas but to carry them through to execution.

Our interprofessional education event (IPE), the pride and joy of Steffens, grew from an idea the Meenans generated to fulfill the foundation's educational mission. Our patient-centric scleroderma-focused interprofessional education event has been and remains a great success, now in the process of being replicated at other centers across the country. Without the Meenans' devoted attention to and advocacy for this project, there would be no IPE. Peter and Linda, we thank you for your devoted service to Steffens. Know the impact of your efforts and know the depth of our appreciation of your work.

2023 IPE

The IPE is undergoing an exciting time of expansion and growth. The annual event is scheduled for the evening of April 12th. This will be a virtual event again, including even more healthcare providers and students than in previous years. In addition, we are making significant headway toward replicating our IPE event at other academic and healthcare institutions.

We are working with professors at Tufts University School of Dental Medicine, Clemson University, staff from Florida International University, and a medical student at the University of South Carolina Greenville to plan IPE replication projects. The first step will be having them attend our April event so they can experience what it is like.

Dr. David Leader will accompany a group of dental students to our virtual event this year. He intends to make Tufts University the hub of this type of patient-centric, scleroderma-focused IPE program in the Boston area.

RESEARCH UPDATES

Degos Disease:

Dr. Shapiro will co-author a chapter with Steffens medical advisory board member Dr. Patrick Whelan of UCLA on "Kohlmeier-Degos disease/malignant atrophic papulosis" for UpToDate, an evidence-based online medical resource. UpToDate is used by 1.3 million physicians around the world and 90% of academic medical centers in the United States.

Abigail Martinez, a medical student and Steffens board member, is pursuing a project on Systemic Degos Long-Term Survivors. This entails qualitative and quantitative quality of life assessments. The purpose is to contribute a positive piece in Degos literature and advocate for individuals living with Degos.

Scleroderma:

George Tawfellos, Nicos Prokopiou, medical students, and Larabe Farrukh, medical resident, are studying lip changes in scleroderma. The four components of the study include:

- Literature review
- Patient questionnaire regarding perception of changes and psychological impact
- Assessment tools for serial study (photography, 3D imaging, thermography, another form of assessment of vascular imaging)
- The potential for drug intervention to mitigate changes

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steffens-scleroderma.org

Dr. Karen Klemper, a tenured professor of Public Health at Clemson and a scleroderma patient herself, is working with Maddy Ryan, a medical student at the University of South Carolina, Greenville, to pilot our IPE model at Clemson, and potentially the medical school at USC Greenville. They are also planning some preliminary lunch and learn sessions with medical students next month. Dr. Shapiro will be traveling to South Carolina for a conference presentation in early April and will meet them. They are all very excited to meet each other in person.

The replication project at Florida International University is also driven by scleroderma patients. Monica Ramirez, a patient, runs a support group in the Miami area. Her daughter became a nurse because of her mother's scleroderma and now works at FIU, where she is actively working on getting a replication program organized. We have the potential for a replication project in South America due to this South Florida connection and are planning on getting our e-book on IPE replication translated into Spanish.

Our board member, Amy Gietzen, is working with several enthusiastic medical students from SUNY Upstate medical college who will be joining us as volunteers for the April event. We again thank the Meenans for their labor and commitment over the years to developing the IPE. It is wonderful to watch their vision begin to come to fruition.



Dr. Michael Hughes

Dr. Michael Hughes BSc (Hons) MSc MBBS MRCP (UK) (Rheumatology) Ph.D. is Consultant Rheumatologist at Salford Royal Hospital, which is a national UK referral center for SSc, and Honorary Senior Clinical Lecturer at The University of Manchester. He has emerged as a leading national and international investigator in SSc and Raynaud's phenomenon, with a focus on novel clinical assessment of vascular biology and function, including the development of new novel approaches to treatment. His doctoral Ph.D. research fellowship (2013-2016) at The University of Manchester investigated the outcome measures of treatment efficacy, pathophysiology, and local treatments for SSc-digital ulcers. Dr. Hughes has a strong research interest in non-invasive imaging and the development of patient-reported outcome measures and works closely with patient-led organizations. He was awarded the Edith Busch Young Investigator Award in recognition of his significant contributions during the World Scleroderma Congress in 2022. Under the auspices of the World Scleroderma Foundation, he leads the Digital Ulcer Working Group, and co-leads the Gastrointestinal disease Working Group. Dr. Hughes has published extensively in both clinical and basic research and has contributed to the development of SSc treatment guidelines and recommendations. He contributes to many international initiatives and collaborations including as a Fellow of the OMERACT Scleroderma Vascular Disease Working Group. He has presented and chaired (including invited oral presentations) at prestigious national and international conferences and is on the editorial board of several international rheumatology journals. Furthermore, he has published several studies in high-impact journals as lead author utilizing data from the EUSTAR cohort. Dr Hughes has graciously agreed to join The Steffens Foundation as a medical advisor. We welcome him with gratitude.

Join us for our annual cruise with the Dutch Apple on the Hudson River for our Cruise for a Real Cure.

July 9, 2023

Please check our website for details.

[Cruise for a Real Cure](#)

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