

# **BREAKING THE CHAINS**

**NEWSLETTER** 

**[une 2022** 

# 5th Annual Interprofessional Education Forum



On April 13, 2022, our 5th successful IPE event was conducted virtually. In attendance were an estimated 207 students representing 8 different healthcare disciplines (OT, PT, Nutrition, Nursing, Public Health, Pharmacy, Medicine, and Psychology). There were 26 patient participants, an expert panel made up of 7 practicing

health-care professionals, as well as up to 30 additional healthcare providers as observers.

New collaborations in this year's forum included students from North Carolina's Wingate University School of Pharmacy, the Dermatology Interest Group (DIG) from Albany Medical College, and University of Albany School of Public Health.

Patients were from widespread, diverse regions of New York State, (Lake George, NYC, Wells, Syracuse, Rochester, West Seneca, Queensbury, Henrietta, Scotia, Queensbury, Niskayuna, and Syracuse). Additional patient participants were from 6 different states (Massachusetts, Vermont, Ohio, Hawaii, and Florida).



To date, as a result of our IPE's, over 1000 emerging health care professionals are entering into their field of expertise with an increased awareness of Scleroderma and its need for specialized treatment. There is potential interest in the replication of the IPE in the format as we have presented it. IPE's have become considered best practice in academic institutions across the country. However, the unique and impactful component of Scleroderma patient participants as educators in an IPE event is not practiced by any other academic institution to our knowledge. There have been inquiries in New York State as well as 4 other states and possibly Canada, to explore duplication of our IPE design in their area.



Thank you our moderators, Michelle Morgan and Jeffrey Brewer.



# How Does the IPE move forward? Interprofessional Education and Scleroderma: Spreading the Word!

We all recognize the incredible value of the one-of-a-kind Interprofessional Education Program developed by the Steffens Scleroderma Foundation and its academic partners: Russell Sage College and Albany College of Pharmacy and Health Sciences. Wouldn't it be great if other programs just like it were hosted all over the country (and beyond!)? The IPE Replication Project Team was established for just this purpose – to spread the word about our program in hopes that others will be as



Jessica Farrell, Pharm.D.,
has achieved the highest level of
Professorship at Albany College of
Pharmacy and Health Sciences.
The Steffens Scleroderma Foundation
Congratulates you and
is proud to have you as our
Associate Medical Officer.



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

August 13, 2022

Please check our website for details.
Cruise for a Real Cure

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## **Donate to Steffens Scleroderma Foundation**

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**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

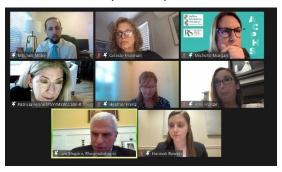
enthusiastic about it as we are, and will create their own version. The project team core team, led by Steve Rosenblum and including Linda and Peter Meenan, Michelle Morgan, Jeffrey Brewer, Amy Gietzen, Heather Frenz, Hannah Bowen and Kerri Connolly (as well as Dr. Lee Shapiro in an advisory role), is taking a three-pronged approach to inspire replication of the IPE: Marketing, Tools and Financing – and there are subcommittees focused on each "prong".

#### **Marketing**

A first draft of a Marketing Plan was developed by Kerri Connolly, focused on reaching three target audiences:

**Patients and caregivers**, including the very active Scleroderma community, for example chapters of the National Scleroderma Foundation and other affinity groups.

**Academic institutions** — many of which have quite robust Interprofessional Education Programs today. We currently have two graduate level students who are doing research to identify the types of IPE and Scleroderma education currently being done by medical and allied healthcare programs. This will help us to identify schools which may be likely to embrace our IPE approach.



Medical and healthcare community, focusing especially on Scleroderma treatment centers. Once we have a good foundation in terms of the target audiences, we will work on developing materials and other strategic marketing tools, including the use of social media, journals, brochures and conference

presentations. There will be presentations about our IPE format at the European League Against Rheumatism (EULAR) conference in Copenhagen in June, the National Scleroderma Foundation in July, and the Canadian Scleroderma Conference in September.

#### **Tools**

The primary tool we are developing at the moment is an Interprofessional Education "how-to" guide we are calling the "eBook". This comprehensive overview of the IPE will be a key tool for those who wish to replicate the program locally. But it is not the only tool we plan to develop — we will also create training videos, online courses, and a database repository of potential IPE participants, including patients and expert speakers. All of these materials will be available through a new "microsite" specifically dedicated to the IPE, and hosted on the Steffens website. We also hope to establish a mentorship program to provide hands-on support when needed.

### **Financing**

In order to successfully complete all of the above tasks, we will need to engage a number of additional resources such as graphic designers, editors and even legal counsel. We will also need to potentially extend our project team resources for several more years. Therefore, we are in an ongoing process of grant applications in order to fund these vital objectives. Grant monies would also allow us to provide seed money to other organizations to assist them in launching their own replica programs.



Thank you all who ordered from our Flower Power fundraiser.

Steffens Scleroderma
Foundation
raised \$512 with
Flower Power Fundraising.



Save the date for our
Fall Event
October 28, 2022
Please go to our website for upcoming details.

**Fall Fundraiser** 



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## **Other Project Focus**

In addition to the IPE Replication, the project team is focused on ways to assess the effectiveness of, and possibly even improve, the existing IPE. If we receive grant money, we will undertake the development of a student-led long-term study to assess the impact of the IPE by contacting past attendees who are now working in the field. The project scope also includes ways for the team to provide assistance to the Education & Awareness Committee and the academic IPE Committee in their quest to continuously improve the program.

If you are interested in getting involved with this existing project, contact Steve at <a href="mailto:srosenblum@steffens-scleroderma.org">srosenblum@steffens-scleroderma.org</a>.



The Art of Advocacy Seminar was developed to provide patients participating in our annual Scleroderma IPE a better understanding of their role and efficacy as educators. A great deal of courage is required for individuals living with Scleroderma to volunteer their time to speak openly and honestly about their medical journey from diagnosis to dealing with daily life and coping with symptoms. The Art of Advocacy was

created by and for patients participating in our IPE in an effort to empower them, and allow the ability to honestly voice with clarity the impact Scleroderma has on their daily lives. One pivotal way to do that is for a person to take ownership of the individual's health journey and find key ways, to articulate it to others. The Art of Advocacy is designed to specifically guide the patient volunteers with strategies to share their individual stories, provide tips from their experienced patients (Amy and Heather) who have participated in various roles within the IPE, and gently guide them to use their personal experiences to educate students.

The Art of Advocacy was debuted a week prior to the IPE event over two separate Zoom seminars facilitated by Amy Gietzen and Heather Frenz in order to accommodate all interested participating patients. The seminar lasted 60 minutes and was extremely well received by all. Moving forward we hope this seminar can serve as a learning tool for all patients recruited to participate in our future IPE



events and add to the overall success of the events for years to come.

Created and presented by: Amy Gietzen – Scleroderma patient, Advocate, Columnist for Scleroderma News, and Board member to the TriState Chapter and The Steffens Scleroderma Foundation and Heather Frenz- Scleroderma patient, Executive Director, Patient Safety & Clinical Competency Center, Albany Medical College.

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