

COLLAGEN CONNECTION

Winter 2015

We are pleased to welcome Dr. Robert Lafyatis to our Center!



Robert Lafyatis is Professor of Medicine and the Thomas Medsger Professor of Arthritis Research at the University of Pittsburgh School Of Medicine. He relocated from Boston University and joined our Division of Rheumatology and Clinical Immunology in September 2015, as Director of the UPMC and University of Pittsburgh Scleroderma Center. He sees patients in our Scleroderma Clinic.

Dr. Lafyatis is a clinical rheumatologist and translational physician-scientist, investigating scleroderma pathogenesis and biomarkers of disease. He is a leader nationally and internationally in systemic sclerosis research. His work includes molecular studies examining the causes of fibrosis, inflammation and autoimmunity. He also studies new medications and has been the lead investigator on several clinical trials

of novel medications for patients with systemic sclerosis.

He has pioneered the use of biomarkers as outcome measures in patients with systemic sclerosis, and shown that these can be used successfully to assess patient responses to medications. Most recently he has shown that blocking one of the main mediators of fibrosis, TGF-beta, leads to dramatic improvement in biomarkers and clinical disease.

Dr. Lafyatis has authored over 120 peer-reviewed articles and a number of book chapters on scleroderma pathogenesis. He has published review articles on topics ranging from SSc treatments to mouse scleroderma models, and autoimmunity and innate immunity.

Dr. Lafyatis chairs review panels for several NIH grant study sections responsible for reviewing research grant proposals. He is also a reviewer of manuscripts submitted to journals including Arthritis and Rheumatology, Journal of Experimental Medicine and Journal of Investigative Dermatology. He co-chairs the International Workshop on Scleroderma Research, which has been held biannually in the UK or Boston USA alternating for over 20 years.

He is a Member of the Planning and Scientific Committees for the Fourth Systemic Sclerosis World Congress.

He has co-chaired multiple sessions on scleroderma pathogenesis at American College of Rheumatology national meetings. The unifying goal in his work is to find better treatments for patients with systemic sclerosis.

Dr. Lafyatis states, "It's a great honor for me to be chosen to lead the Pittsburgh Scleroderma Center with its very rich history of achievement in understanding the disease. I am very excited to work with the team of investigators already at the University of Pittsburgh, including Dr. Domsic, who will lead and work with me in the clinic and with Dr. Fuschiotti, who will help me in translational studies. I am anticipating the continuing close interactions between the clinicians and scientists at UPMC is going to permit us to make major advances in treatment over the next few years, and continue in the tradition of Pittsburgh as the premier center for clinical care and research into scleroderma."

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DR. SHIOW-BIH LIN AND FAMILY SUPPORTS SCLERODERMA RESEARCH

When Dr. Shio-Bih Lin relocated to Pittsburgh from Taiwan 35 years ago, her first position in the United States was at the University of Pittsburgh Medical Center (UPMC), where she rotated at Presbyterian Hospital, Magee Women's Hospital, and Children's Hospital of Pittsburgh. Since then, she has devoted her life to medicine. She was practicing pediatrician and now assists her husband, a urologist, at his office. Today, Dr. Lin still visits UPMC, but in a much different capacity than she did nearly four decades earlier – this time as a patient at the UPMC and University of Pittsburgh Scleroderma Center.

“Going back to UPMC is like going home,” she said. “I really appreciate everything that the doctors and researchers at the Scleroderma Center have done to care for me, and to find answers regarding this orphan disease.”

When Dr. Lin began to experience scleroderma symptoms, including muscle weakness, fatigue, and gastrointestinal bloating, she visited her primary care physician, rheumatologists and gastroenterologists for tests. Months later, it was finally a senior rheumatologist who asked if she thought it could be scleroderma, and referred her to Dr. Thomas Medsger at the UPMC Scleroderma Center for further diagnosis and treatment. “As a physician, scleroderma never crossed my mind. The disease is rare. I never thought something so serious could happen to me. But now I know that I am in good hands.”

Since her diagnosis, Dr. Lin has made numerous lifestyle adjustments, the primary one being to work less. She

now works on a part-time basis, takes several different medications at strict intervals, watches her diet, and is careful to listen to her body and not over exert herself. “I wake up every morning and feel grateful for life, and I really appreciate it,” Dr. Lin said. “Every day is a new chance.”

In an effort to support scleroderma research, Dr. Lin made a generous donation to the UPMC and University of Pittsburgh Scleroderma Center. Her daughter also made a contribution in appreciation of the care her mother has received at the UPMC Scleroderma Center, especially the dedication of Dr. Medsger. Dr. Lin believes that although pioneers in the field such as Dr. Medsger, have discovered much about the disease, much more needs to be solved – and that can be done only through research.

“Research is costly, and our current medical research efforts need a lot of funding,” she said. “There's a lot to learn about scleroderma, such as how to cure it – I want to help wherever I can, and my daughter feels the same. Even if it doesn't help me, it will

benefit people in the future.”

In order to learn more about the disease, Dr. Lin and her family (husband, daughter, and son), attended the Scleroderma Foundation Patient Conference last July in Nashville, TN. She knows that the knowledge they gained at the conference gave them all a much better understanding of scleroderma so they know what to expect and can thoroughly stand by one another as a family. They also cheered that Dr. Kathryn Torok from Children's Hospital of Pittsburgh Scleroderma Center was honored as “Doctor of the Year 2015” by the Scleroderma Foundation.

“It's important to realize there's still a lot to learn,” Dr. Lin said. “I have a great support system, and that keeps me calm. Understanding the disease and taking it one day at a time will get us closer to finding a cure.”

If you would like to learn more about how you can support the UPMC and University of Pittsburgh Scleroderma Center, please contact Gary Dubin at 412-647-9113 or dgary@pmhsf.org.



Dr. Shio-Bih Lin, along with her husband and children, enjoying their time at the 2015 Scleroderma Foundation Patient Conference in Nashville, Tennessee.

CONGRATULATIONS DR. CASSIE TOROK 2015 SCLERODERMA FOUNDATION DOCTOR OF THE YEAR



Robert Riggs, CEO of the Scleroderma Foundation, poses with Dr. Kathryn Torok

Dr. Kathryn "Cassie" Torok juggles patients in her clinic, conducting her own research, and mentoring the next generation of pediatric rheumatologists. She has played an instrumental role in shaping the workshops and panel discussions for the growing national juvenile scleroderma program as was obvious at the July 2015 National Patient Education Conference in Nashville.

Dr. Torok is the director of the Pediatric Scleroderma Clinic at the Children's Hospital of Pittsburgh. She dedicates her time to seeing patients, who she calls her "kids." She has a reputation for evaluation and treatment of children with all forms of scleroderma.

Dr. Torok is an Assistant Professor of Pediatrics at the University of Pittsburgh School of Medicine. She is involved in both local and national clinical and laboratory research efforts to move forward the field of pediatric scleroderma, both localized scleroderma and systemic forms. This includes her role as the principal investigator of the National Registry for Childhood Onset Scleroderma

(originally established by Dr. Thomas Medsger in 2002). She is co-investigator and biorepository director of the juvenile localized scleroderma consensus treatment program and other collaborative research efforts of multiple U.S. pediatric scleroderma centers which are members of the Childhood

Arthritis and Rheumatism Research Alliance (CARRA).

In addition to supporting the Scleroderma Foundation's educational programming, she works closely with our local and regional Arthritis Foundation as a board member.

We are very grateful for all of the recent donations to support pediatric scleroderma research!



Carly Bankovich participated in a student council event called the Penny War, a competitive fundraising game.



Alyssa Finney and Cindy Gabor created a teal scleroderma themed quilt for a raffle that raised \$1400.



Chloe Robinson and her family's connection with the Circle of Swords Gaming Guild led to a fundraiser at a recent convention.

WALK WITH TORI 2015

The 5th annual Walk with Tori was held on September 13th in Hagerstown, Maryland. The outpouring of support is amazing every year. Doctors and staff from the UPMC and University of Pittsburgh Scleroderma Center were there to collect blood donations to aid in their research.

Tori's family and friends have organized the walk to bring awareness about the disease and to raise money to support research at the Center. All monies raised at the event are used for scleroderma research. Over the past five years, Tori and her family and friends have raised over \$150,000!

Thank you to all who came out to support the walk and those who donated blood.

All photos courtesy of Triple-T Photography, Hagerstown, MD





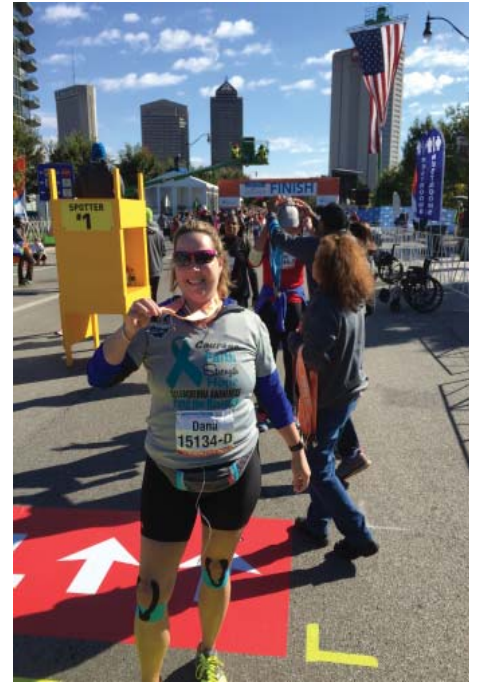
CENTER STAFF MEMBER COMPLETED HALF MARATHON FOR SCLERODERMA AWARENESS

Dana Ivanco, one of our Center research coordinators, ran and finished the Columbus Half Marathon on October 18th to raise awareness for Scleroderma. The shirt she wore was designed by Marla Bowen, a scleroderma patient.


If you are interested in ordering a shirt, please visit the online store:

<https://awareness.itemorder.com/sale>

All proceeds benefit scleroderma research.



Dana poses with her medal and Marla Bowen, the designer of the shirts.



Do you have a question regarding scleroderma that you would like answered by our Scleroderma Center team of experts?

Please send your question to Maureen Laffoon at laffoonm@pitt.edu

If your question is selected, the question and answer will be published in a future issue of the newsletter.

Thank You

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