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.”
When Dr. Shiow-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. 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.

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

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

Our Scleroderma Center is committed to participating in clinical trials. We currently have four actively recruiting drug trials, which are described below. In the next six months, we will enter 3 additional trials. We hope that if you are eligible that you will consider participating. We will be happy to speak with you to answer any questions you may have. Please contact one of our scleroderma research coordinators, Dana Ivanco at des2@pitt.edu or Maureen Laffoon at laffoonm@pitt.edu.

CURRENTLY ENROLLING PATIENTS:

The Effect of Atorvastatin on Microvascular Endothelial Function and Raynaud in Early Diffuse Scleroderma (TAMER): This is a NIH-supported single-center study (being done only in Pittsburgh) examining the effect of atorvastatin (Lipitor) on Raynaud symptoms and small blood vessel function in patients with early diffuse scleroderma. Early disease is <3 years of scleroderma symptoms in this study. Scleroderma is characterized by blood vessel injury, immune system activation and fibrosis. The blood vessel injury is thought to be important early in the disease, and many think this may be the reason so many patients experience Raynaud as the first symptom. While atorvastatin reduces cholesterol, it is recognized to have many positive effects beyond cholesterol reduction. These include improvement of blood vessel function and reduction of fibrosis. Because of these effects, it is believed that atorvastatin will improve blood vessel function and Raynaud symptoms in patients with early disease. The trial is 16 weeks and half the patients will receive atorvastatin and half placebo. Atorvastatin (or placebo) is given as an "add-on" therapy. This means all medications can be continued while in this trial. There are only 3 visits over 16 weeks.

A Study of Subcutaneous Abatacept to Treat Diffuse Cutaneous Systemic Sclerosis (ASSET): This study examines the safety and effectiveness of abatacept in patients with early diffuse scleroderma (<3 years of symptoms). Abatacept (trade name Orencia) is a medication which has been FDA-approved since 2005 for the treatment of rheumatoid arthritis. It is administered as an injection (at home) once weekly. In this study half the patients will receive drug and half the patients will receive placebo over one year. At the end of that year all patients are allowed to enter the open-label treatment where they are guaranteed to receive drug and not placebo.

Rituximab (Rituxan) Study: Rituxan is an immunosuppressive drug originally designed to treat lymphoma, but has been FDA-approved to treat rheumatoid arthritis. Rituximab eliminates B cells from the blood stream. These cells participate in immune responses and may be responsible for some types of immune injury to tissues in patients with rheumatoid arthritis, lupus, and other related diseases, such as scleroderma. This study is directed at Scleroderma patients who have confirmed pulmonary arterial hypertension (PAH or high blood pressure in the lungs) regardless of how much skin thickening they have. Rituximab is given by vein twice, two weeks apart. Half of the patients will receive rituximab and half placebo. A right heart catheterization both before the study (to determine eligibility) and after 6 months on treatment (or placebo) is required. Other PAH medications can be continued throughout the study. Patients will be followed for 1 year or until the B cells in their blood have returned.

UPCOMING TRIAL:

Scleroderma Treatment With Celution Processed Adipose Derived Regenerative Cells (STAR): This trial is intended to assess safety and efficacy of subcutaneous administration of Celution processed self-derived regenerative cells into fingers of patients with hand contractures as a complication of their scleroderma. Participants will undergo liposuction to harvest a small volume of fat. This will be done under local anesthesia. The fat aspirate will then be processed in the Celution System to isolate and concentrate the regenerative cells to be injected into each of the fingers on both hands (also under local anesthesia). Half of the participants will be randomly assigned to receive their own regenerative cells, and half will receive a solution without regenerative cells.

JBT-101 is an experimental (investigational) drug that is chemically similar to a chemical in cannabis, or marijuana. However, this drug has been designed to avoid the “high” feeling of marijuana. This research study is being done to test the safety, tolerability, and efficacy of JBT-101 when it is given to subjects with diffuse cutaneous scleroderma of < 6 years of disease. JBT-101 is entirely manufactured from chemicals, not plant or animal products. This is a 16 weeks study. Patients will be able to remain on their current scleroderma medications. 2 out of 3 will receive therapy in this study, and 1 in 3 will receive placebo.

A Phase 2, Double-blind, Randomized, Placebo-controlled Multicenter Study to Evaluate Safety, Tolerability, Efficacy, and Pharmacokinetics of JBT-101 in Diffuse Cutaneous Systemic Sclerosis: JBT-101 is an experimental
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.
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.

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.
We would like to thank the following donors for their support of scleroderma research:

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