

CONQUER

Collaborative, National Quality and Efficacy Registry

Patient Newsletter

In this second issue of the CONQUER Patient Newsletter, we wanted to provide you an update on the CONQUER Registry. We are proud to announce that Dr. Ami Shah, a CONQUER investigator at Johns Hopkins University, was awarded the prestigious Henry Kunkel Young Investigator Award. CONQUER investigators have presented their research at the American College of Rheumatology National Virtual Meeting and were invited to apply for a Department of Defense Award. The CONQUER team has published another manuscript in *Clinical Rheumatology*. We are pleased to bring on additional sites to improve diversity of the CONQUER cohort. Lastly in this issue, we give an update on the COVID-19 vaccination. We continue to thank you for your research participation and interest, and the Scleroderma Research Foundation and Boehringer-Ingelheim for sponsoring this resource for discovery.

Featured CONQUER Investigator

Dr. Ami Shah, the chair of the CONQUER Science Committee, was named a 2020 recipient of the Henry Kunkel Young Investigator Award from the American College of Rheumatology. This award honors an early career physician scientist who has made outstanding and promising independent contributions to basic, translational or clinical research in the field of rheumatology. As the chair of the CONQUER science committee, Dr. Shah reviews all research proposals that are submitted to CONQUER for scientific value and integrity. We are grateful for her commitment to systemic sclerosis and very proud of her remarkable achievement in the field of rheumatology and contributions to CONQUER.



Telemedicine Update

The CONQUER registry adapted to the challenges of care delivery during the pandemic with Telemedicine. If you were unable to see your provider in the clinic, you are encouraged to reach out to your provider to see if telemedicine is an option. Patients with less than 5 years disease duration are encouraged to meet with their rheumatologist every 6 months. Your virtual visit can be tied to the questionnaires that you complete. These Patient Reported Outcomes (PRO) are forms are designed to capture how you feel and function. In the CONQUER registry these can be provided by survey link sent to your email. If you do not receive them please let your physician know. Additionally, your blood contains important markers that can help our researchers understand disease progression and response to treatments. For CONQUER, your blood is processed locally and shipped overnight to the Biorepository. The blood sample is a critical aspect of CONQUER discovery work. If you are having virtual visits, but are going to the lab to have routine blood work, please notify your physician so that we can possibly coordinate collection of CONQUER labs.

CONQUER Sites and PI:



Columbia: Elana Bernstein

Georgetown: Virginia Steen

George Washington: Victoria Shanmugam

HSS: Jessica Gordon

Johns Hopkins: Laura Hummers and Ami Shah

Massachusetts General: Flavia Castellino

Univ. of Michigan: Dinesh Khanna

MUSC: Faye Hant

Northwestern: Chase Correia

Univ. of Penn: Nora Sandorfi

Stanford: Lori Chung

Univ. of Texas-Houston: Shervin Assassi

University of Utah: Tracy Frech



CONQUER Research Update

Over the past year, CONQUER presented two research presentations on interstitial lung disease at the American College of Rheumatology National Meeting, which is the premier rheumatology meeting in the United States. CONQUER was invited to submit a grant to the Department of Defense to examine biomarkers of lung disease. We also published research on “Does hand involvement in systemic sclerosis limit completion of patient-reported outcome measures?” in a peer-reviewed medical journal, *Clinical Rheumatology*. In this manuscript, we reported that resorption of bone at the fingertips (acro-osteolysis) and calcinosis was associated with a reduction in completion of patient-reported outcomes. Our goal is to have 100% completion for patient reported outcomes, so please talk to your physician if hand pain is limiting your ability to complete these and the research coordinator will help you. Your voice is important for us to learn how systemic sclerosis impacts your life!

Update on the COVID Vaccine

Multiple COVID vaccines are under development. Vaccines are tested in large clinical trials to make sure they meet safety standards. In these trials people of different ages, races, and ethnicities, as well as those with different medical conditions, are evaluated. Systemic sclerosis patients have not been specifically studied for COVID vaccines. Nearly all COVID vaccines being studied in the United States require two shots. The first shot starts building protection, but everyone has to come back a few weeks later for the second one to get the most protection the vaccine can offer. The Pfizer-BioNTech and Moderna vaccines use a genetic molecule, known as mRNA, that is packaged so that it can fuse to a cell, allowing the molecule to slip in. The cell uses the mRNA to make proteins from the coronavirus, which can stimulate the immune system to make protective molecules known as antibodies. The immune protection provided from antibodies generated by these vaccines may last for months or perhaps even years, but their mRNA does not — it is destroyed by immune cells within days. Although these are described as “genetic” vaccines, the vaccines do not alter your genes in any way. So far, no COVID vaccine has been approved for children. New vaccines are typically tested on adults before researchers launch trials on children, and COVID vaccine developers are following this protocol. It is recommended that adult systemic sclerosis patients receive the vaccine. The vaccine will be distributed by state, so if you receive care across state lines you should establish a care provider in your state who can administer the vaccine when it is available. The FDA and CDC will continue to monitor the safety of COVID vaccines, to make sure even very rare side effects are identified and reported.