

January 2022

Patient Resources

The M.U.S.C.L.E. Research Group would like to provide you with resources to assist you in meeting your best care.

- *Medication Resources*
- *Community Resources*
 - Housing
 - Utilities
 - Food Assistance
 - Non-emergent Medical Transportation
 - Mental Health
 - Primary Medical and Dental Care
 - Free Clinics
 - Legal Help and General Services for Disabled Individuals

Please follow the link below to learn more!
[Lupus Patient Education Day Resources 2021 \(muscedu\)](https://www.musc.edu/lupus-research/patient-education-day-resources-2021)

Interested in Our Research?

Visit [SCresearch.org](https://www.scresearch.org) → Search Studies:
use keyword *lupus*

Revamping Our Newsletters

Look out for our next newsletter in the coming months!

Tell us what you'd like to see in our future newsletters by emailing your ideas to us at:
lupusresearch@muscedu

10th Annual Lupus Patient Education Day (October 2nd 2021)

Patients, Families, and Friends -

The Division of Rheumatology and Immunology at MUSC thanks you for attending our MUSC/ Duke University co-sponsored event!

To those who were unable to attend or would like to review what was shared during our Lupus Patient Education Day, feel free to contact us at lupusresearch@muscedu for a copy of our presentation.

M.U.S.C.L.E



Medical University of South Carolina
Lupus Erythematosus
Research Group



Some Takeaways from Lupus Education Day:

- The MUSCLE Team is proud to have participated in 3 trials that have led to the development of 3 new FDA-approved medications to treat lupus and lupus nephritis over the past year.
 - [Belimumab](#) (Benlysta)- approved for active lupus nephritis (was approved for non-renal lupus in 2011)
 - [Voclosporin](#) (Lupkynis)- approved for active lupus nephritis
 - [Anifrolumab](#) (Saphnelo)- approved for active non-renal lupus

As we learn more about the immune system pathways affected by lupus, additional targeted therapies with less side effects will become available (30 other agents are currently in the works!)

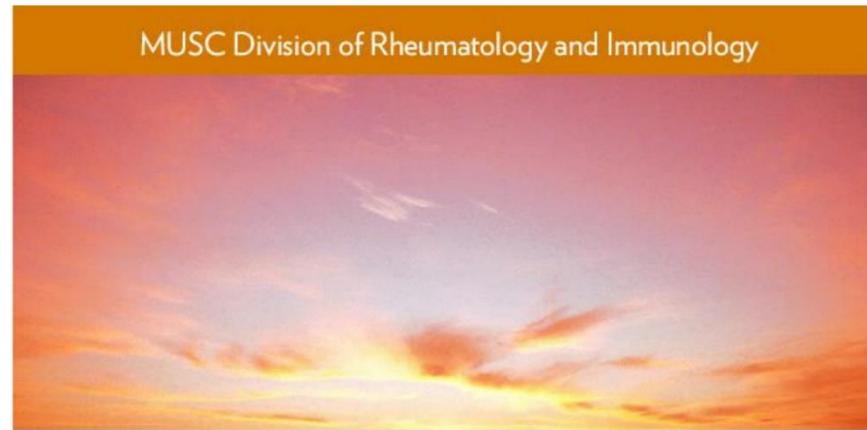
- Get the most out of your rheumatology visits and your partnership with your provider with these communication tips:
 - Prepare before each visit:
 - Bring an updated med list. Discuss medication side effect concerns, costs of medications, or how to take these medications.
 - Bring a family member or friend to help you remember details discussed during your visit.
 - During visit:
 - Discuss primary complaint at start of visit and agree on realistic goals for the treatment of your disease with your provider.
 - Let your provider know if you have any questions about your disease and what the outcome may be with and without treatment.
 - Let your provider know if you have had any new problems/ hospitalizations/ procedures.
 - Tell your provider if you are having any new signs or symptoms of a flare.
- Some lupus medications suppress your immune system, which increases risks associated with COVID-19 illness. The CDC recommends that lupus patients receive all 3 COVID-19 shots (2 for J&J vaccine) that are currently available, as well as a booster shot 6 months after your last dose.

Please visit www.lupus.org for more info!

We need your thoughts on lupus research at MUSC!

Join our Participant Engagement Group in Spring 2022. Patients with lupus and family members are needed for a 90-minute focus group to share thoughts and provide feedback on MUSC research participation and research studies related to lupus.

If you are interested in being contacted with further information, please visit redcap.link/lupuspeg to fill out our interest form.



Family and Friends, Volunteers WITHOUT a history of lupus or scleroderma can help us find answers!

Our research focuses on two autoimmune connective tissue diseases; scleroderma and lupus.

The goal of our research is to answer specific questions about these rheumatic diseases and it is hoped that the information gained will increase our knowledge and help in the treatment of future patients.

You can play an important role in Changing What's Possible at MUSC

Most participation involves a 1-time visit to our campus to complete simple surveys/questionnaires and provide a biological sample such as blood, urine, saliva and/ or skin sample. Contacting our team does not obligate you to participate. Our study staff will review our currently enrolling studies with you to determine what study might be the best fit for your participation interest.

Contact Us: 843-792-3926 or lupusresearch@musc.edu

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