



The GOAL Report

Lupus News You Can Use!

2022 - Year in Review



In 2005, I was 17. I got really sick and weak. I couldn't walk far without being out of breath. I was in much pain and lost a lot of weight in a month. I couldn't eat or keep water down; I was throwing up my stomach lining. The doctors couldn't figure out what was wrong with me. My blood dropped to 3, and the doctors couldn't believe I was alive, let alone walking around.

After a few months, I was diagnosed with Autoimmune Hemolytic Anemia. I had a Splenectomy in 2010 to

eliminate the antibodies eating my red blood cells. My blood has been stable since.

In 2013 I developed Panniculitis & fibromyalgia. I had lupus symptoms, but it took 11 years for the test to come back positive in 2016 finally. Now I get Rituximab infusions every six months. I'm in constant pain, fatigue, and bald spots. The pain meds don't stop the pain just make it bearable. I've been a Lupus Warrior for 17 years.

GOAL Participant Research Insights

Here are highlights of our research based on three participants' perspectives:

Jasmine's research motivation:

- Participating in research can compare symptoms and help find new treatments.
- Research helps me by allowing me to see if others are experiencing the same symptoms.
- It allows me to keep myself up and going despite how I feel daily. Trying to enjoy life the best I can with this illness keeps me going.
- Participating in research means I get to share my experience and symptoms in hopes of helping someone else and help find treatments.

Special topics of interest:

- I'm interested in hearing more about patients with not just typical lupus symptoms but also different symptoms. I'm always told I'm very rare and have complex lupus. I would like to know if others share my symptoms and learn some things they do to manage them and have a better quality of life.
- I hope to learn about more treatments, find others with my symptoms, and learn some different things I can do to manage symptoms better or minimize the symptoms to have a better quality of life.



Melanie's research motivation:

- Hopefully, feedback from patients will help with better plans of action for treatments.
- When I was first diagnosed, I made mistakes like not finding a lupus specialist. I hope that doing research and giving ideas on what worked for me and what to watch out for may help someone else down the road.
- Research helped me find a rheumatologist who was a lupus specialist. I also learned to ask questions regarding steroid use planning, including how to taper and the length of time.

Special topics of interest:

- Pain management, steroids cause weight gain, which is hard to drop with joint pain.
- I hope they are about to find a holistic approach to lupus pain management that goes with the other medications, like Rituximab with intravenous immunoglobulin.
- Exhaustion, without caffeine, I often could nap anywhere, anytime. I am always exhausted, even with good sleep.

Melanie has been a GOAL study participant since 2007! We have approximately 600 GOAL participants who have participated in our research studies for at least ten years!



Michael's research motivation:

I was diagnosed in 2010 and had been living with lupus for about 11 years going on 12 years. My coping strategies for living with lupus are praying, staying in the loop of all lupus things, eating healthy, being consistent with medications, taking daily vitamins, and decreasing stress. I know stress is associated with lupus flares, so I try to keep my stress levels low. I try to stay calm and happy, knowing this is my reality and that I must make the best of the situation. I have good doctors; I feel valued and listened to during my appointments. My doctors answer my questions and give me vital information that I listen to and take seriously by following their recommendations. I try to do the right things, stay active, eat healthier, and be attentive and consistent with my medical care, trying to attend all doctor appointments.

Special topics of interest:

- any chance of finding a cure. Participating means a lot to me. I do a lot of research and reading on lupus. It keeps me up to date with lupus-related news and discoveries. And how new findings could potentially benefit me.
- What motivates me are outcomes! I like the results, I want to see what more needs to be done, like further research. I am also inspired by just knowing what is going on with lupus research.
 - I want more studies on environmental factors that may cause lupus flares and other associations that may bring about a lupus flare.
 - I want a cure for lupus. If not a cure, I would like more discoveries of medicines that can stop future flares and keep the disease activity low so patients can live a better, happier, and healthier lifestyle.

Michael has been a GOAL Study participant since 2011! He enrolled within one year of his lupus diagnosis. Approximately 160 of our active GOAL participants enrolled within two years of diagnosis. We have about 90 men participating in our research.

This is Michael's story...

- I participate in research to learn more about the disease and if there is



Thank you for your contributions to our lupus research!

The table below is a list of our GOAL-related projects. The one or two long surveys you get from us each year are the main GOAL & SOUL surveys. These are the most important, and based on interest and eligibility, you may be invited to participate in the other studies. Other opportunities will come if you have yet to be approached for additional studies. We are deeply grateful for your time, effort, and contributions. We will continue to fight daily to ensure your voice is heard.

Project	Purpose	Method	Participant commitment
Main Outcomes Projects			
Main GOAL & SOUL	To learn more about the health of Georgians with lupus and the impact of social determinants of health. This research will also help us understand lupus patients' problems with getting health care.	Survey-based	2-surveys per year Long-term study (No fixed end date)
SOUL validation	To evaluate skin lesions and monitor the progression of skin conditions associated with lupus.	In-person visits	1 or 2 visits over the course of 2 years
Collaborative Projects			
VISTA	To assess how the thoughts, feelings, and emotions impact changes in the blood vessels of African American women with SLE aged 18-45 without previous heart disease.	In-person visits and surveys	3 in-person study visits over the course of 2 years and 2 questionnaire surveys
APPEAL	To learn more about the burden of physical and mental factors impacting the health outcomes of people with lupus.	In-person or virtual study visits	1 study visit (Completed 5/2022)
Community Self-management Support Projects			
SELF-GOAL Program Evaluation	To assess the impact of an online self-management program on outcomes associated with people with lupus.	Use of web-based programs and surveys	3 months of the SELF program, 1 follow-up survey, and optional interview
Lupus Patient Navigator Program	This program aims to support lupus patients through overall disease management by working with a patient navigator to provide support and resources.	Lupus Foundation of America (LFA) program	Participants work with a patient navigator who provides emotional support, education, and links to community resources.
WELL	To better understand how a self-management program improves health outcomes and reduces healthcare use in African American women with lupus.	Attend weekly self-management program for 6 weeks, interviews and surveys	6 in-person sessions, baseline and follow-up surveys, optional interviews (Completed 3/2022)
IDEAL	To assess the value of educational information using a shared decision-making approach given on a tablet about the risks and benefits of lupus medications to people with lupus.	In-person discussions and surveys	a 30-minute engagement during a clinic visit and 2 follow-up surveys at 3 and 6 months (Completed 12/2022)
Digital Health Coaching Program	To evaluate how digital health coaching affects the exercise habits, health, and well-being of Black, African American, and Latina women with SLE.	Lupus Initiative program. Participants will be randomly assigned to either receive standard care and a digital education packet or be assigned a health coach.	All participants involved in the study will receive a FREE Fitbit Inspire and will be asked to use it to track daily activity. Periodic surveys. (Completed 4/2022)
PALS	This is a peer education program for people living with lupus. Learn about lupus health and clinical trials. (Pilot)	Lupus Therapeutic and KDH program	Participants virtually connect one-on-one with someone else with lupus. (Completed 12/2021)



ABOUT GOAL PARTICIPANTS

NUMBER
OF GOAL
PARTICIPANTS

1405

DURING 2022... YOU HELPED US TO MAKE THE FOLLOWING FINDINGS:

- The SOUL Study findings emphasize the psychosocial challenges people living with primary skin lupus face. Stigmatization and social isolation may lead to depression. Public health awareness campaigns about disfiguring conditions may help to reduce stigma.

- During the COVID-19 pandemic, many participants reported improved confidence in managing symptoms, medications, and other treatments. Although there were trends showing participants receiving more emotional support, there were no significant changes in overall global mental and physical health.

- Need for more information regarding the purpose of lupus clinical trials. Support groups and peer connections (like the PALS Program) are comfortable for candid discussions.

- The VISTA Study found associations between Adverse Childhood Experiences and more pain interference (the extent to which pain hinders engagement with various activities, including sleep and enjoyment of life) and bodily pain.

- The WELL Study found that self-efficacy (one's belief in their capacity to execute behaviors necessary to maintain health and other goals) was inversely related to fatigue. While more self-efficacy reduced the intensity of fatigue, pain and depression increased the intensity.

AVERAGE
DURATION LIVING
WITH LUPUS

11.5 YRS

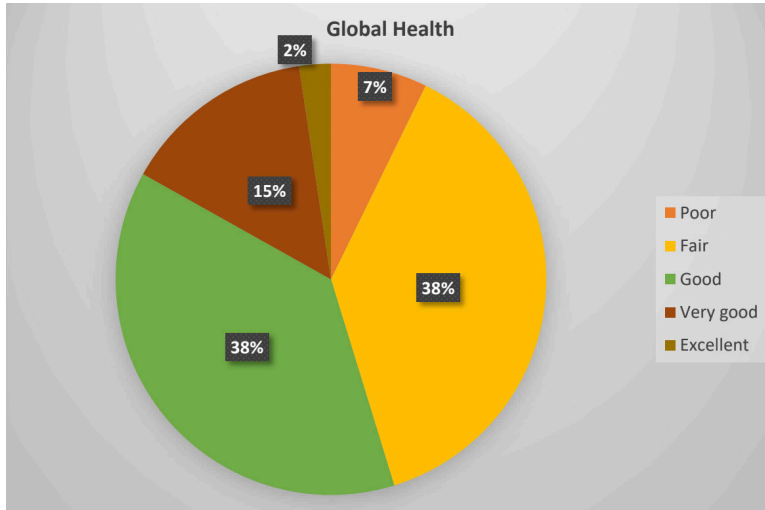
AVERAGE AGE
AT THE TIME
OF SURVEY

43.8

RESEARCH RESULTS

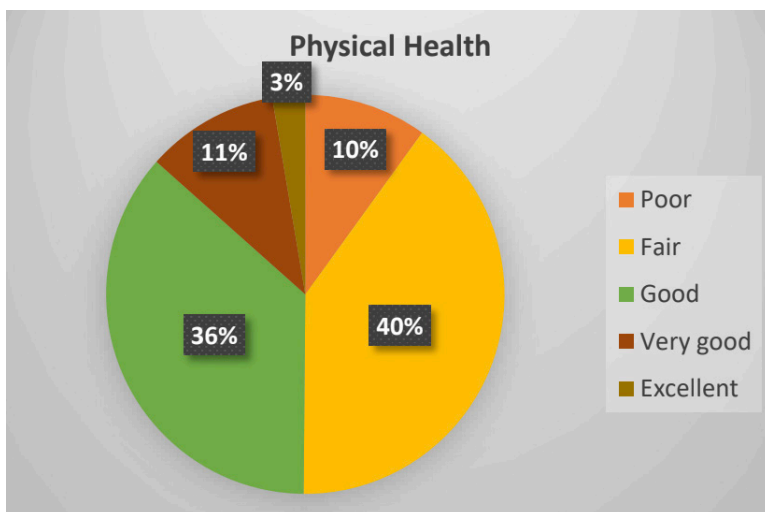
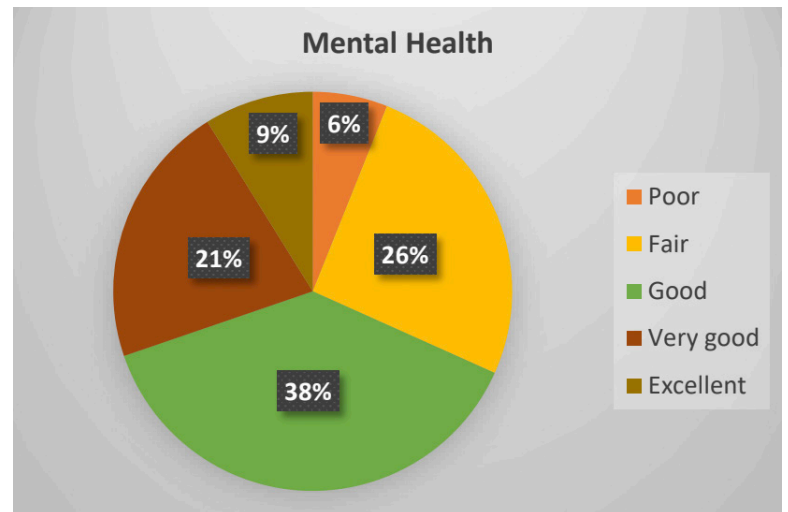
2021 – 2022: 763 Survey Responses

Your shared responses allow us to show the widespread impact of lupus on physical, mental, and social health. To assess this, we use well-established and recognized questionnaires to measure health outcomes from the patient perspective. It is intended to reflect your assessment of your health globally.



IN GENERAL, WOULD YOU SAY YOUR HEALTH IS: EXCELLENT, VERY GOOD, GOOD, FAIR, OR POOR?

IN GENERAL, HOW WOULD YOU RATE YOUR MENTAL HEALTH, INCLUDING YOUR MOOD AND ABILITY TO THINK: EXCELLENT, VERY GOOD, GOOD, FAIR, OR POOR?



IN GENERAL, HOW WOULD YOU RATE YOUR PHYSICAL HEALTH: EXCELLENT, VERY GOOD, GOOD, FAIR, OR POOR?

We continue to be inspired to learn and search for more ways to support you! Here are our plans for 2023!

Main Outcomes Projects			
Project	Purpose	Method	Estimated Collection Time
GOAL	<ul style="list-style-type: none"> Identify social determinants of health that predict health outcomes in systemic lupus. Identify work-related challenges. 	Surveys completed by web, mail, or telephone	March 2023 – December 2023
SOUL	<ul style="list-style-type: none"> Identify social determinants of health that predict health outcomes in cutaneous lupus. Identify work-related challenges. 	Surveys completed by web, mail, or telephone	March 2023 – December 2023
GOAL & SOUL	<ul style="list-style-type: none"> Identify ongoing COVID-19-related challenges. Identify the impact on lupus. 	Surveys completed by web, mail, or telephone	October 2023 – December 2023

Lupus Patient registries allow clinical data collection to identify health access needs and disease burden and ultimately help improve health care quality. We are excited to have the opportunity to contribute to population awareness regarding lupus in other areas outside of metro Atlanta.

GA Lupus Registry 2 (lupus patients in South Georgia)			
GLR2	<ul style="list-style-type: none"> Identify the number of people with lupus in South GA. Invite them to join GOAL. 	Working with Rheumatologists and other healthcare providers in South GA.	January 2023 – December 2023

We look forward to your continued shared experiences through surveys, other studies, and our discussions by telephone, email, or in person. We value and appreciate your time and efforts as a GOAL Participant!

Best wishes from the GOAL Team,

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Dr. Jessica Williams
Dr. Cristina Drenkard
Hilton Mozee
Aita Akharume
Meaza Girmay
Jessie Black
Gaobin Bao
Charmayne Dunlop-Thomas



EMORY
 UNIVERSITY
 SCHOOL OF
 MEDICINE

Help Us Solve
The Cruel Mystery

LUPUS™

FOUNDATION OF AMERICA
GEORGIA CHAPTER

The Lupus Foundation of America (LFA) Georgia Chapter continues to provide our GOAL members with LFA Memberships filled with educational and social support resources. We applaud LFA for their extraordinary efforts as the nation's leading nonprofit voluntary health organization dedicated to finding the cause of and cure for lupus and their exemplary support services to all people affected by lupus!

If you have any questions or changes in contact information, please get in touch with us today!

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