

SIP 21-008 Examining approaches to improve care and management of people with lupus



Emory Prevention
Research Center

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Co-Principal Investigator: S. Sam Lim, MD, MPH

- Professor of Medicine and Epidemiology
- Emory University Department of Medicine and Rollins School of Public Health
- Chief of Rheumatology, Grady Health System

Co-Investigator: Cristina Drenkard, MD, PhD

- Associate Professor of Medicine and Epidemiology
- Emory University Department of Medicine and Rollins School of Public Health

Charmayne Dunlop-Thomas, MS, MPH

- Associate Director of Research Projects
- Emory University Department of Medicine

Gaobin Bao, MPH

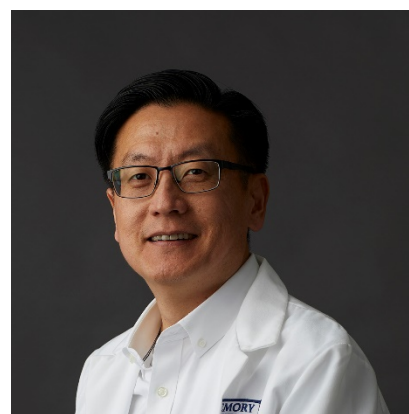
- Senior Biostatistician
- Emory University Department of Medicine

Mary Crimmings, BA

- Senior Vice President of Marketing and Communications
- Lupus Foundation of America

Melissa French, MS

- Content Director
- Lupus Foundation of America



S. Sam Lim, MD, MPH

Both mental and physical health are consistently reported to be worse in people with systemic lupus erythematosus (SLE) compared to those with diabetes, heart disease, and other chronic conditions, in large part due to the systemic involvement, challenging diagnosis and management, and multiple comorbidities that often come with having SLE. This is exacerbated in Black individuals by their disproportionate burden of SLE prevalence, poor outcomes, comorbidities, and poor health-related quality of life. Successful self-management of SLE requires having the skills to engage in effective daily activities, which often comes from having access to up-to-date health education and self-management support. Currently, there are no widely available, evidence-based, SLE-specific self-management resources.

Our proposal leverages two on-going Centers for Disease Control and Prevention (CDC) supported efforts with synergy in resources and timing to uniquely and powerfully achieve our aims. The CDC-supported, population-based Georgians Organized Against Lupus (GOAL) Cohort is a prospective cohort of validated and consented individuals with SLE that reflects “real world” lupus in the community in and around Atlanta, Georgia. The Lupus Foundation of America was supported by the CDC to develop an online lupus self-management program based on the Transtheoretical Model of Behavior Change called Strategies to Embrace Living with Lupus Fearlessly (SELF), which helps users adopt key self-management behaviors. We propose two aims over a two-year period. Aim 1 will examine behavioral and psychosocial factors and their association with patient reported outcomes using already collected data from the GOAL Cohort. Aim 2 will examine changes in patient reported outcomes after being exposed to SELF in the GOAL Cohort.