Project CHANGE

by Lupus THERAPEUTICS

an affiliate of **LUPUS** RESEARCH ALLIANCE

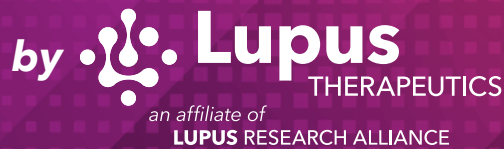## Centering diversity, equity, and inclusivity in clinical research so those most affected by lupus can best benefit from new treatments.

What is Project CHANGE by Lupus Therapeutics (LT)?

People of color are vastly underrepresented in lupus clinical research, despite lupus affecting them two to three times as often as Caucasians, and often with greater severity of disease. Lupus Therapeutics and Lupus Research Alliance, with the support of our collaborators, developed Project CHANGE by LT to address this systemic challenge head-on.

Project CHANGE by LT stands for:

(C)	(H)	(A)	(N)	(G)	(E)
COMMUNITY-BASED	**HEALTH**	**ACTION**	**NETWORK TO**	**GENERATE TRIAL PARTICIPATION**	**ELIMINATE DISPARITIES**

Project CHANGE by Lupus Therapeutics is a groundbreaking approach that will ensure people of color receive the education and tools needed so that they are well represented in clinical research, empowered to make decisions about research and, receive the best possible support and care when choosing to participate. We are determined to improve representation of people of color in lupus research by bringing together all the various groups that can help — healthcare providers, advocacy groups, women's health groups, and local community leaders — to better understand the barriers and co-create solutions that will really work, for the people who need them most.

Why is Project CHANGE by LT so Important?

Because lupus affects each person very differently, it is especially important for the full range of patients living with lupus to participate in research so that we can work towards a cure for everyone. However, too often treatments are not adequately tested among the people who will need them most, and basic clinical research, including health questionnaires and taking biological samples, lack diversity. Project CHANGE by LT will increase representation by people of color in lupus clinical research, particularly African Americans, so potential new treatments can be developed, tested, and used by the patients who need them most. We are focused on increasing participation in a way that engages the whole community, with the patient at the center.

What barriers will Project CHANGE by LT address?

Project CHANGE by LT will address the many factors that contribute to the lack of diversity in clinical research. We will address healthcare providers' inherent biases which limit opportunities among people of color to participate in trials, concerns about the loss of these patients to the clinical trial process, and their overall limited ability to address and help patients overcome their concerns.

We will also work to develop trust and awareness among lupus patients and communities of color to appreciate the need and benefit of participation. We recognize that people living with lupus have concerns about taking part in research, including potential costs, fears of being a "guinea" pig, and potential side effects of an unapproved drug. There is also historic mistrust of the healthcare system due to systemic practices which prevent engagement and inclusivity, and the very real daily challenges including lack of childcare, eldercare, transportation to trial sites and lack of paid time off from work.

And we will tackle powerful system-wide barriers such as funding policies that impact who is given the opportunity to join a trial, racism that further lowers patient trust in the healthcare system, lack of health insurance, and lack of healthcare providers of color to serve patients of color seeking the reassurance of healthcare providers who look like them.

Why should individuals and organizations join Project CHANGE by LT?

By joining Project CHANGE by LT, you can not only help individual patients living with lupus, but also help improve the lives of millions of Americans in communities across the country. Even for those who are not specifically interested in clinical studies, your involvement may have value in terms of learning about clinical research and supporting the broader community in conversations about it. Lupus Therapeutics is confident that our collaborative community-based approach will provide the full range of perspectives to finally unravel the subtle nuances of the existing barriers and together create a model that works and can be tailored for other geographic areas and disease states. To learn more, contact Lupus Therapeutics Director of Health Equity Ebony Scott at Escott@LupusResearch.org.

How does Project CHANGE by LT work?

The three-year program is being implemented in the following major phases from formation through evaluation and reporting:

1 We are establishing a steering committee to select localities/communities to pilot the project as a Lupus Research Collaborative (LRC), which will work with patients; hospitals; healthcare providers; women's health groups; medical and nursing associations; medical, community-based, faith-based, and grass root organizations; as well as community leaders to tailor a specific Action Plan that fits each of their community's particular needs.

2 Lupus Therapeutics will fund and provide ongoing assistance to each LRC to implement their intentional Action Plan.

3 A unique evaluation plan will be implemented to track, understand and evaluate the outcomes, challenges and successes of each LRC so we can learn how to replicate the process in other situations.

How is Project CHANGE by LT supported?

Lupus Therapeutics and the Lupus Research Alliance are working with a diverse array of collaborators and our own Lupus Clinical Investigators Network of 57 academic medical centers throughout North America to conceptualize, implement and guide Project CHANGE by LT. Because increasing representation of diverse lupus patients in clinical research is so vitally important, in addition to Lupus Research Alliance and Lupus Therapeutics financial resources, Project CHANGE by LT also has the partial support of major pharmaceutical companies.

Contact:

Ebony Scott
Director of Health Equity, Lupus Therapeutics
Escott@LupusResearch.org