



# Health Equity, Patient Engagement, and DEI efforts at Lupus Research Alliance

# About Lupus Research Alliance

- **The Lupus Research Alliance** is the largest non-governmental, non-profit funder of lupus research worldwide. The organization aims to transform treatment by funding the most innovative lupus research, fostering diverse scientific talent, and driving discovery toward better diagnostics, improved treatments and ultimately, cure for lupus.
- **Lupus Therapeutics:** As the clinical research accelerator arm of Lupus Research Alliance, we partner with biopharmaceutical companies, clinical investigators, and community organizations to improve the clinical research process. Our efforts have one ultimate goal – ensuring the lupus community has more therapies that better address the unique ways lupus can affect individuals.



# Hope Inspired by Progress



# About Lupus

- Lupus is a complex, potentially life-threatening autoimmune disorder that **disproportionately impacts women and communities of color**.
- Lupus can affect the joints, skin, brain, lungs, kidneys, and blood vessels, causing **widespread inflammation and tissue damage** in the affected organ.
- A heterogenous disease, lupus affects each person differently and its effects can change over time, making it **one of the most difficult diseases to diagnose and treat**.
- Black, Hispanic, Asian, and Native American populations **are two to three times more likely** to be diagnosed with lupus than white populations.





# Prioritizing Health Equity and DEI at LRA:



- Bolstering Internal DEI Efforts
- New Strategic Plan Centers Equity & Engagement









# Patient Engagement at LRA/LT


- **PALS (Patient Advocates for Lupus Studies)**
  - Early educational intervention delivered by peers to improve clinical trial participation
  - Pilot (Phase I) concluded Fall 2021
- **Patient Advisory Boards**
  - Bring the patient voice as a partner to the drug development table and prioritizes the patient needs and preference
  - Gain insight into disease burden while examining clinical research barriers and motivators
- **Patient Protocol Review Council**
  - Incorporates patient voice early in protocol development and review process
  - Helps to design protocols that are less burdensome and more meaningful for patients


# PALS

Patient Advocates for Lupus Studies

by  **Lupus**  
THERAPEUTICS  
an affiliate of  
LUPUS RESEARCH ALLIANCE

Composite Score	Intervention group scored higher than control at posttest on all outcomes
Knowledge	
Attitudes	
Self-efficacy	
Intentions	

 Statistically significant increase

 Increase

## Model for Successful Patient Engagement: Patient Advocates for Lupus Studies

- **9** out of **11** trained PALS identified as **women of color**.
- **68%** of PALS participants identified as **Black/African American**, while **13%** identified as **Hispanic**.
- Individuals who completed the PALS program demonstrated significant increases in **knowledge** about, **attitude** towards, and **intention** to participate in lupus clinical trials following completion of the PALS program.
- Treatment participants also demonstrated increases in **self-efficacy** three months after finishing the program.
- Additionally, participants expressed **high satisfaction** with the program overall.





# Diversity in Lupus Research Program

- ***Career Development Award to Promote Diversity in Lupus Research*** provides up to \$600,000 over four years to outstanding early-career underrepresented minority scientists to establish an independent research program aligned with LRA's strategic priorities.
- ***Postdoctoral Award to Promote Diversity in Lupus Research*** provides promising underrepresented postdoctoral research fellows with \$170,000 over two years to support projects and the generation of data needed to become an independent lupus researcher.
- ***Administrative Supplement to Promote Diversity in Lupus Research*** supports, for up to two years, promising underrepresented minority trainees working with LRA-funded researchers or lupus investigators supported by the National Institutes of Health or Department of Defense who have reviewed LRA grant applications within the past three years.



# Lupus Nexus & Landmark Study



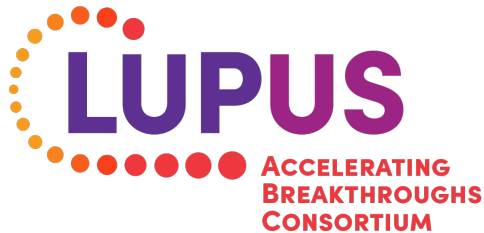
- Lupus Nexus is first-of-its-kind lupus registry, biorepository, and data exchange platform that aims to accelerate lupus research and translation.
- Created with lupus patient advisory council
- Biorepository and platform allow interactive a platform where individuals living with lupus, researchers, healthcare providers, and advocates can connect, share insights, and collaborate

# LuCIN Health Equity Working Group

- The LuCIN Community Health Equity Working Group brings together investigators and team members from across the LuCIN Network to identify strategies, efforts, and resources needed to enable the network to increase health equity and improve diverse representation in lupus clinical trials.
- As the premier lupus clinical trials network in North America, the LuCIN Network is uniquely positioned to have profound impact on the access, inclusion, and outcomes for those historically underrepresented in lupus clinical trials.



# Lupus Research Alliance Unites the U.S. Food & Drug Administration (FDA) & Lupus Community to Launch Novel Public-Private Partnership



## Goals of Lupus Accelerating Breakthroughs Consortium

### Accelerate Therapies

Bring together federal agencies, industry, academic clinical researchers, medical societies, patient advocacy groups, and people with lupus to address the most pressing obstacles to drug development and implement an action plan that has the greatest, most immediate impact on advancing lupus treatments.

### Expand Scientific Collaboration

Facilitate an open, collaborative, and community-wide approach that connects the best and brightest minds in lupus research, helping partners share knowledge, conduct key research projects, and catalyze patient-focused lupus drug development.

### Elevate the Voices of People with Lupus

Unite people across the lupus and research communities to ensure that the experiences, perspectives, needs, and priorities of people with lupus are meaningfully incorporated into the development of new lupus treatments.





# Lupus Voices Council



# Lupus Therapeutics Healthcare Provider Directory™

The screenshot shows the top of the website. On the left is the logo for Lupus Therapeutics, an affiliate of the Lupus Research Alliance. On the right are navigation links: About, Industry Solutions, and Patient & Community Engagement. Below the navigation is a hero image of a woman sitting on a green sofa using a laptop. A purple overlay on the left contains the text 'Lupus Therapeutics Health Care Provider Directory™'. Below the image is a button that says 'Join The Healthcare Provider Directory'. Further down is a section titled 'Find a Provider or Clinical Trial Center' with a paragraph of text explaining the directory's purpose and a search tool with a text input field and a distance dropdown set to 50 miles.

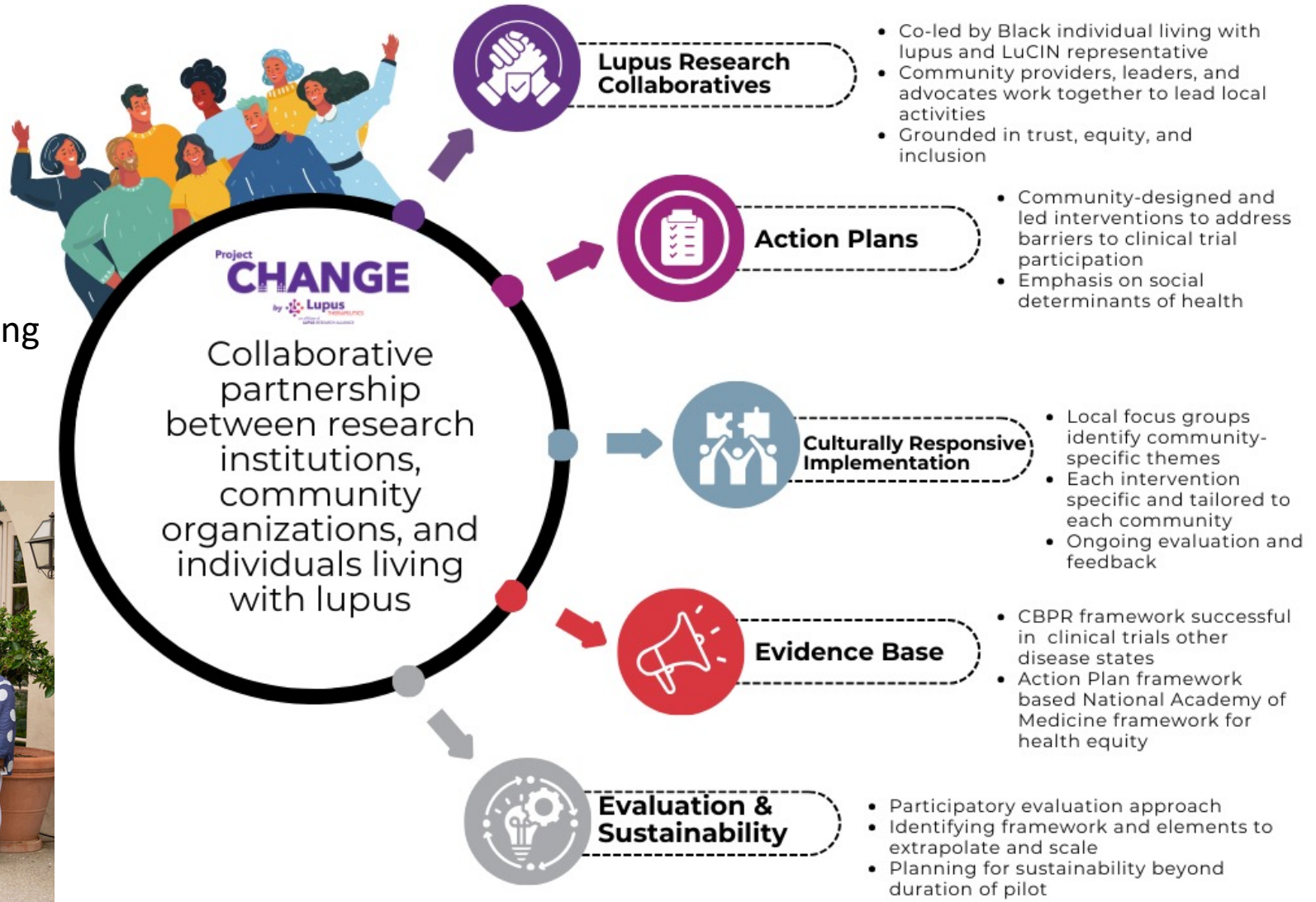
The image displays four provider profile cards arranged in a 2x2 grid. Each card includes the provider's name, institution/practice, specialty, and contact information. A circular 'LuCIN Center' badge is present on each card.

Provider Name	Institution/Practice	Specialty	Payments
<b>Cristina Arriens, MD, MSCS</b>	<b>Oklahoma Medical Research Foundation - Rheumatology Center of Excellence</b>	Rheumatology	Medicare Private Insurance
<b>Anca Askanase, MD</b>	<b>Columbia University Irving Medical Center, Dept of Medicine Rheumatology</b>	Rheumatology	Medicare Private Insurance
<b>Laura Aspey, MD, MPH</b>	<b>Grady Memorial Hospital</b>	Dermatology	Medicare Medicaid Private Insurance
<b>Antonio Avina-Zubieta, MD, MSc, PhD, FRCP</b>	<b>Mary Pack Arthritis Centre, Arthritis Research Canada</b>	Rheumatology	Medicare Columbia

- First-of-its-kind in lupus
- Launched 08Nov2023 - ~300 providers to date
- Core: LuCIN center providers
- Community practices surrounding LuCIN centers
- Support for clinical care and access to clinical trials

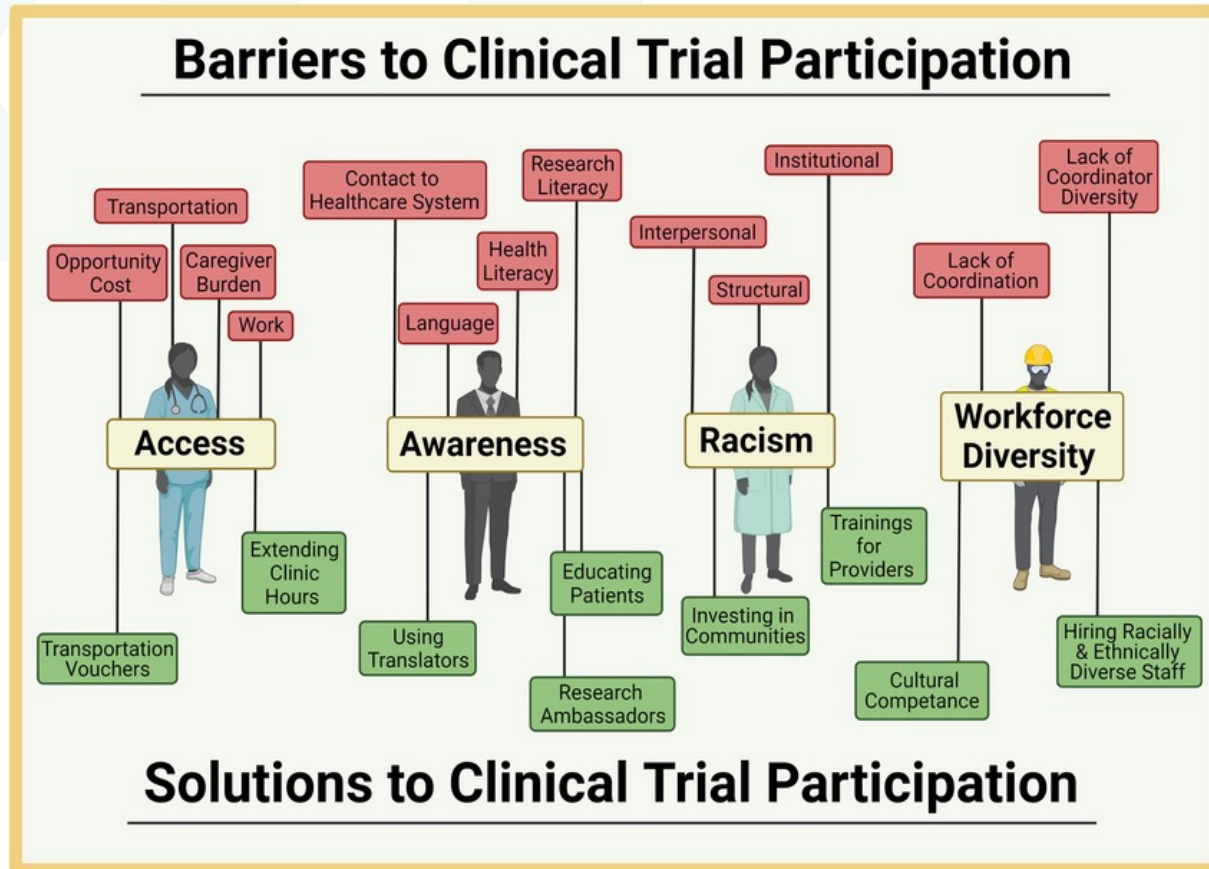
# Project CHANGE

Community-based Health Action Network to Generate trial participation and Eliminate disparities is a community driven approach to increase lupus clinical trial representation among Black and African American individuals





# Background for Project CHANGE Framework



- Black, Hispanic, Asian, and Native American populations are two to three times more likely to be diagnosed with lupus than white populations and often have greater severity of disease.
- Black individuals make up 43% of lupus cases but account for just 14% of clinical trial participants.
- Evidence suggests that observed disparities in health outcomes in lupus are **largely due to differences in opportunities to achieve optimal health.**

- Sheikh SZ, Wanty NI, Stephens J, Holtz KD, McCalla S. The State of Lupus Clinical Trials: Minority Participation Needed. J Clin Med. 2019 Aug 17;8(8):1245. doi: 10.3390/jcm8081245. PMID: 31426523; PMCID: PMC6722692.
- Ioannis Parodis, Cristina Lanata, Dionysis Nikolopoulos, Ashira Blazer, Jinoos Yazdany, Reframing health disparities in SLE: A critical reassessment of racial and ethnic differences in lupus disease outcomes, Best Practice & Research Clinical Rheumatology, 2023, 101894, ISSN 1521-6942, <https://doi.org/10.1016/j.berh.2023.101894>.

# Project CHANGE Team

## Project CHANGE Steering Committee

**Edith Williams, PhD**  
Steering Committee Co-Chair



Medical University of South Carolina  
[wiled@musc.edu](mailto:wiled@musc.edu)

**Salathiel DeLoach**  
Steering Committee Co-Chair



DeLoach Lupus Foundation of Savannah, GA  
[deloach03@hotmail.com](mailto:deloach03@hotmail.com)

**Carla Boutin-Foster, MD**



SUNY Downstate Health Sciences University  
[carla.boutin-foster@downstate.edu](mailto:carla.boutin-foster@downstate.edu)

**Dexter Cooper, MPH**



KDH Research & Communication  
[dcooper@kdhrc.com](mailto:dcooper@kdhrc.com)

**Cary Goodman**



The Balm in Gilead, Inc  
[cgoodman@balmingilead.org](mailto:cgoodman@balmingilead.org)

**Jessica Williams, MD**



Emory University School of Medicine  
[jessica.williams2@emory.edu](mailto:jessica.williams2@emory.edu)

**Hetlena Johnson**



Quartz Health Solutions & Lupus SC  
[hjohnson@lupuscsc.org](mailto:hjohnson@lupuscsc.org)

**Kim Quan**



IDEO  
[kquan@ideo.com](mailto:kquan@ideo.com)

**Tom Antony, MBA**



IDEO  
[tantony@ideo.com](mailto:tantony@ideo.com)

**Soledad Alfaro, MEd**



Surge Institute  
[salfaro17@gmail.com](mailto:salfaro17@gmail.com)

**Chris Reed, JD**



Eljiga Health Solutions  
[Christopher.reed@live.com](mailto:Christopher.reed@live.com)

## Lupus Therapeutics Team



Claire Finney, MPH  
Associate Director,  
Health Equity

Taylor Adjei, MPH  
Senior Program  
Coordinator, Health  
Equity

Stacie Bell, PhD  
Executive Vice  
President, Lupus  
Therapeutics

## LuCIN Centers



## Research & Evaluation Partners



DECISION INFORMATION RESOURCES, INC.

- Sylvia Epps, PhD
- Tiara Jackson, PhD
- Cynthia Castaldo-Walsh, PhD
- Ventrice Shillingford-Cole, MPH
- Oriana Perez, MPH
- Jill Helmick



KDH RESEARCH & COMMUNICATION

- Nikki Wanty, MA
- Dexter Cooper, MPH

# Coming Up: LRA Walk to Cure Lupus and more



2024 WALKS

<a href="#">South Florida</a> Sunday, March 3	<a href="#">New York City</a> Saturday, October 19
<a href="#">New Jersey</a> Saturday, May 4	<a href="#">Dallas</a> Saturday, October 19
<a href="#">Northern Michigan</a> Saturday, June 8	<a href="#">San Diego</a> Saturday, November 2

DON'T SEE A LOCATION NEAR YOU?

[JOIN THE VIRTUAL WALK ON OCTOBER 19TH](#)



# Contact Us and Learn More



Claire Finney, MPH

Associate Director, Health Equity

• [cfinney@lupusresearch.org](mailto:cfinney@lupusresearch.org)



Taylor Adjei, MPH

Senior Program Coordinator, Health Equity

• [tadjei@lupusresearch.org](mailto:tadjei@lupusresearch.org)

