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
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.

<table>
<thead>
<tr>
<th>Composite Score</th>
<th>Intervention group scored higher than control at posttest on all outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge</td>
<td>🚀</td>
</tr>
<tr>
<td>Attitudes</td>
<td>🚀</td>
</tr>
<tr>
<td>Self-efficacy</td>
<td>🚀</td>
</tr>
<tr>
<td>Intentions</td>
<td>🚀</td>
</tr>
</tbody>
</table>

🚀 Statistically significant increase

Increase
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
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™

- 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.
• 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.

---


Coming Up: LRA Walk to Cure Lupus and more
Contact Us and Learn More

Claire Finney, MPH
Associate Director, Health Equity
  • cfinney@lupusresearch.org

Taylor Adjei, MPH
Senior Program Coordinator, Health Equity
  • tadjei@lupusresearch.org