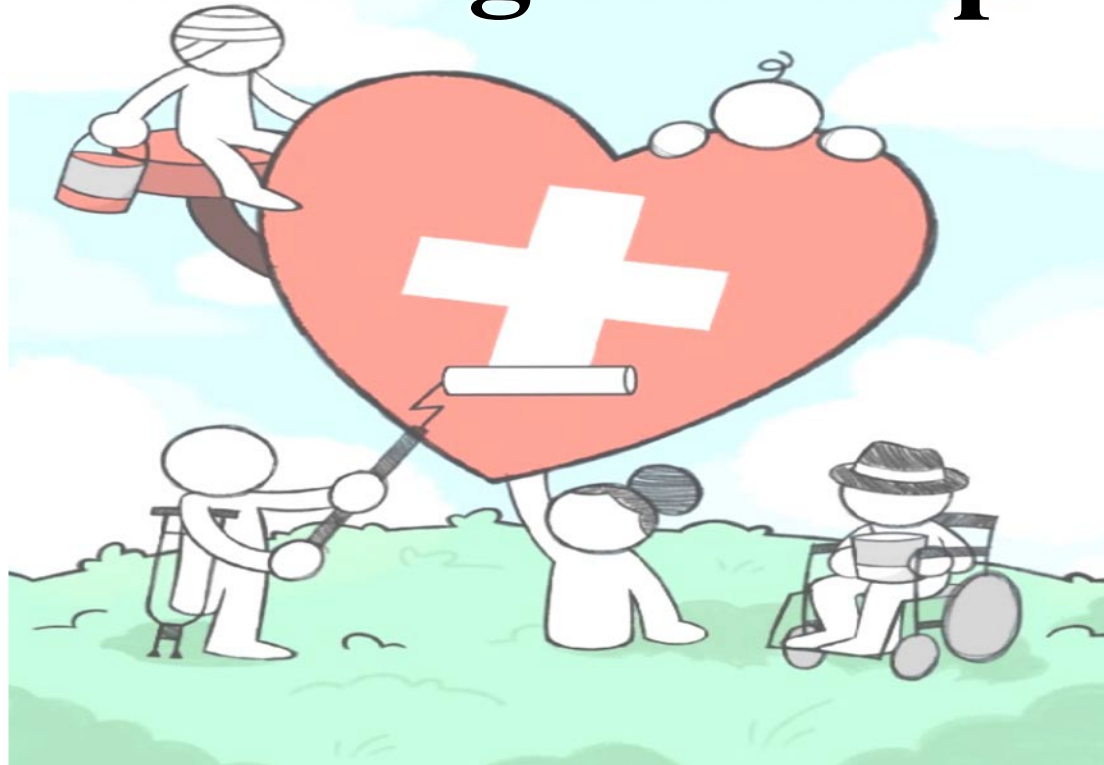


Improving Care in Lupus- Closing the Gap



17th Annual Lupus Education Day

November 4, 2023

Edith M. Williams, PhD, MS

Founding Director

Office of Health Equity Research (OHER)



UNIVERSITY of ROCHESTER

Relationship



UNIVERSITY of ROCHESTER


Commitment to diverse recruitment

- **Benefits of diverse recruitment of research participants and study team members**
 - Essential to have a wide range of people from different communities participate in clinical trials
 - Ethical and research consequences of lack of diversity
 - Diverse teams are smarter
- **Strategies to ensure diverse recruitment**
 - Consider placement of recruitment materials
 - Restructuring of job postings, rethinking qualifications, ensuring competitive wages to accommodate less traditional roles
 - Less daunting incentive and remuneration processes



Alignment of IRB's with DEI priorities

- **IRB's charged with addressing the ethics of inclusion in clinical research**
 - Ethical oversight of diversity in their procedures to encourage enrollment of minorities
- **Inclusion imperative**
 - To encourage belonging
 - Importance of D & I in board committees
- **May require training/skill building**
 - Effective recruitment strategies
 - Cultural sensitivity



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September 1, 2020

Hello!

I am developing a peer mentoring program for African American women with lupus. The Peer Approaches to Lupus Self-management (PALS) study is designed to help African American women with lupus (mentees) develop and practice self-management skills by pairing them up with another African American woman with lupus (mentor) who can demonstrate these skills and encourage and support her mentee. Participants in this research study are randomized to either having a mentor or going to a support group. **If you are interested in being mentored, please contact Dr. Edith Williams by October 30, 2020 (contact information below).**

Who PALS Is Looking For

Mentees who:



- Have been diagnosed with lupus
- Speak English
- Have a desire to improve their health
- Have ability to try strategies to better manage their lupus


Mentees who can commit themselves to:

- Four questionnaires, which you will be compensated for
- 1-2 hours every two weeks for 24 weeks by phone or video chat with your mentor
- Sharing your progress for us to track how well the program is working


Through participation in the program, mentees have the chance to improve their health-related quality of life, self-management, and disease activity. This mentee experience also provides the opportunity to enhance interpersonal relationships, develop skills that are transferrable to other fields, and enrich your current job and/or life.

Looking forward to meeting you soon!


 Dr. Edith M. Williams, PhD, MS
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IRB Number:
Pro00080875
Date Approved 08/21/2018



"An equal opportunity employer, promoting workplace diversity"



Protected time for relationship building

- **Importance of researchers having protected time for relationship building**
- Building equitable and sustainable partnerships is important:
 - Work is made easier
 - Research is more transparent, representative of community interests and needs, effective, and impactful
- Institutions can:
 1. Mandate a priori engagement with communities of interest (vulnerable communities)
 2. Incentivize faculty for meaningful activity and visibility within the community
 3. Assign value and support community-based activities
 4. Recognize relationship building/partnership formation in T & P process



Ensuring basic needs are met

- **Basic needs of communities of interest should be met/addressed prior to approaching about research involvement**
 - Survival
 - Health care
- **Tale of Two Cities**
 - MUSC lupus navigator
 - Health Equity Program Support Office at URM
- **Encourages equitable research**
 - Builds trust
 - Requires institutional backing



A photograph of a man and a woman standing side-by-side, both dressed in purple. The man on the left is wearing a purple top hat, a light purple long-sleeved button-down shirt, and dark trousers with a brown belt. He is holding a pair of glasses in his right hand. The woman on the right is wearing a purple wig, a dark purple top, a long purple feathered scarf, and purple gloves. She has her arm around the man's shoulder. The background is a plain, light-colored wall. The text "Questions???" is overlaid in the center in a white, serif font with a slight glow.

Questions???

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