

Lupus Clinical Trial Journey

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Learning Objectives

- Brief introduction my lupus journey and experience in trials.
- 2 Programs that I am apart of concerning Lupus and clinical trials.
- The importance of diversifying the clinical trial participant pool
- Identifiable Barriers preventing participation in clinical trials
- Key facts around recruitment and engagement of clinical trials
- Benefits of Clinical Trial Participation



My Lupus Journey

- Diagnosed with Systemic Lupus Erythematosus on July 3, 2003
- Diagnosed with Antiphospholipid Syndrome 2014
- Diagnosed with Lupus Nephritis in 2016



My Trial Journey

First became aware of clinical trials during my first hospital stay (and initial dx) from my rheumatologist at Children's Memorial Hospital in 2003.

Types of trials I have participated in:

- Interventional
- Observational
- Behavioral



PALS (Patient Advocate for Lupus Studies)

2019 joined LRA Lupus Research Alliance as a PAL

What is a PAL?

- Patient Advocacy
- Clinical trial education and awareness
- Supporting Lupus patients



Lupus Conversations

2020 joined Lupus Conversations as a POL Popular Opinion Leader

- Educational Training to share with the community (social networks, community networks etc)
- Share clinical trial awareness (fact sheets, flyers etc)
- Using various platforms to share information about health and scientific research about clinical trials
- Build Partnerships



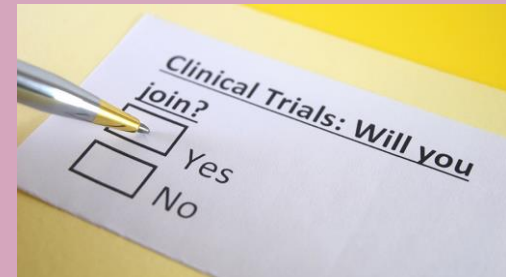
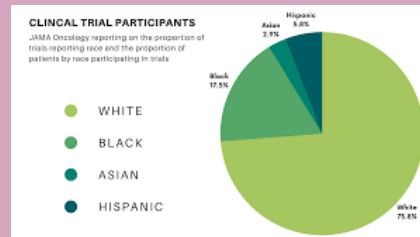
Barriers to Clinical Trials

- Fear of being a guinea pig
- Not understanding lupus diagnosis
- History of mistreatment while in the clinical trial
- Having a “ if it’s not broke don’t fix it” mindset
- Not having a trusted partner in the medical sector (doctor, nurse, case manager)

HEALTH

Your Drugs Probably Weren't Tested On People Of Color

Medical research doesn't reflect America's diversity, and it's created a health and economic disaster.



Addressing Barriers

- Community Interaction with researchers
- Education is key
- Cultural Competency Training for staff (doctors, researchers, nurses) inclusive of listening and
- Consistent interaction with the community
- Follow up about Clinical trial care



The Importance Clinical Trial Participation

Clinical trial participation is important because...

- It allows researchers to have a better understanding of the disease
- Opportunities for additional healthcare treatment and access to new improved medication
- Medication Coverage
- CURE!



My Why

- Lupus complications that I have endured
- CURE!
- Representation Matters! More people of color are needed for clinical trials.
- Progression towards treatments and medication that will continue to treat the disease and not the symptoms
- More representation from patients impacted the most by the illness
- Increasing researchers' knowledge of the disease in hopes of finding a cure.

