LRAN
Lupus Research
Action Network

by Lupus Foundation of America

Suggested Talking Points

The talking points below are designed to assist you in speaking about clinical trials at support group meetings, Lupus & You events and other community events.

We do not expect you to be an expert on Clinical Trials, nor to have all the answers. In your role as an LRAN member, your goal is to educate your peers about trial participation, and to share information on what you learned at the LRAN trainings.

In working with your LFA staff partner, please use any points you think are important for your audience to hear, taking into consideration the amount of time you have to share this information. Also, please share information about enrolling in RAY, which is a critical resource through which people with lupus can learn more about clinical trials.

1. Introduction

- Introduce yourself, share your lupus experience (diagnosis experience, what it's like for you to live with lupus/how it has impacted your life)
- Share the need for more treatments (in your own words, why is this important for you (fewer side effects, more effective treatments, improved daily life, improve work/school and family life, among other reasons)

2. Importance of Clinical Trials and Diversity in Clinical Trials

- Clinical trials include studies that research potential new treatments to determine if they are safe and effective. Trials also help determine in which groups of people a new treatment may be most effective since not every treatment works the same in every person.
- Participation in lupus trials is needed in order to find new treatments, including for Black/African American women and other women of color.
- While lupus is ranked in the top 10 leading causes of death for Black and Hispanic/Latino women ages 15 to 44 years and Black people are estimated to make up 43% of lupus cases, they are only 14% of participants in lupus clinical trials.
- Increased participation by the Black/African American lupus community will help ensure trials determine whether new treatments are safe and effective for them.

3. What Does it Mean to Participate in a Trial

- General
    - Participation is voluntary – you can disenroll at any time.

    - Clinical trials have a research team that is led by a research/study coordinator and may include doctors, nurses, social workers and other healthcare professionals. They check the health of the participant at the beginning of the trial, give specific instructions for participating in the trial, monitor the participant carefully during the trial, and stay in touch after the trial is completed. Some clinical trials involve more tests and doctor visits than the participant would normally have for their lupus.
    - Strong regulations and laws are in place to protect your safety and your rights.

- Benefits
    - Play an active role in your own health care.
    - Gain access to potential new treatments before they are widely available.
    - Obtain expert medical care during the trial. Participants in trials often receive more comprehensive care than those who do not participate in trials.
    - Receive compensation, in some instances, for your participation. You also may receive compensation for transportation and other costs of participating in addition to covering costs for your medical care associated with the trial.
    - Help other lupus warriors by contributing to medical research.

4. **Where can I learn more (share the RAY flyer)**

- Enroll in RAY (Research Accelerated by You, Lupus.org/RAY)
    - RAY is an online lupus research platform where people with lupus and caregivers share information about their lupus experience to help researchers better understand the disease and accelerate the development of new treatments.
    - By enrolling in RAY, you also will receive information about clinical trials, research studies, focus groups and other opportunities for you to help advance lupus research and improve care.
- National Resource Center on Lupus
    - Search for lupus clinical trials: https://www.lupus.org/get-involved-in-research/search-for-clinical-trials