THE POPULAR OPINION LEADER MODEL AND CLINICAL TRIALS

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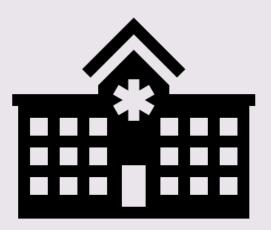
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Lupus Conversations Clinical Trials Popular Opinion Training Module 1

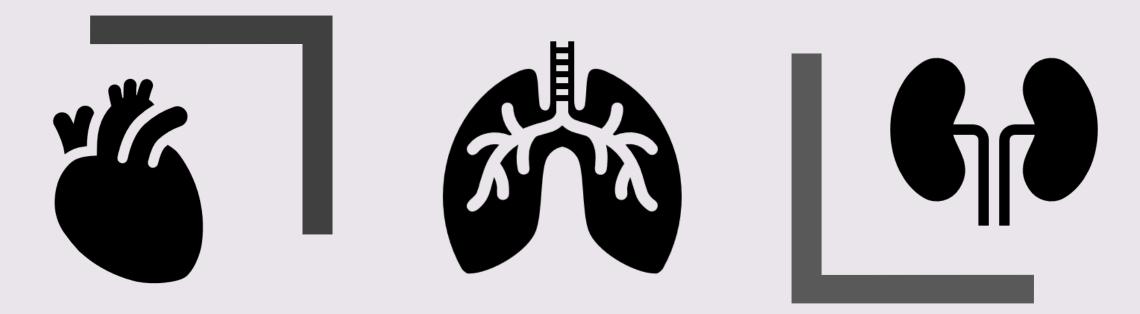
Background and Introduction

Lupus Clinical Trials Program

- 4 year partnership between health centers and communities to increase lupus awareness
- Use the Popular Opinion Leader (POL)
 Model to Lead Community Education
 Strategies
- Use Social Networks to Educate Communities About Chronic Diseases

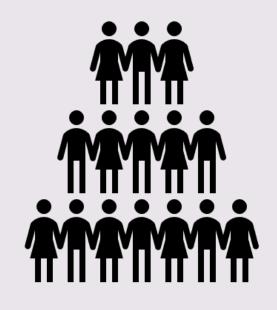






Background on Lupus

- Lupus is a **chronic (permanent) inflammatory disease** that can affect any organ of the body
- The causes of lupus are still unknown
- Lupus is not a contagious (like the flu) or hereditary disease (like sickle cell disease)





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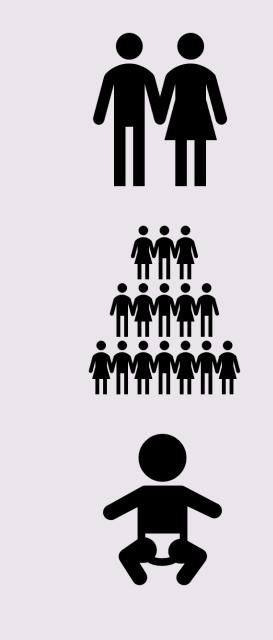
How Common is Lupus?

Prevalence- a measurement of all individuals affected by a disease at a particular time (Center for Disease Control and Prevention)

In 2008, the United States had a lupus prevalence of about 161,000 patients with definite lupus and 322,000 with definite or probable lupus (Helmick et al., 2008)

How Common is Lupus?

- Different Populations have Different Prevalence Rates for Lupus
 - ✤ Blacks (128 people/100,000)
 - American Indians/Alaska Natives (178/100,000 people)
 - ✤ Hispanics (90.5/100,000 people)
 - **Asians** (94.7/100,000 people)
 - All have higher prevalence rates than Whites (47.5/100,000 people)
- Lupus can affect people of any age, race or ethnic origin, and gender identity, and there is no way to prevent lupus





The Popular Opinion Leader (POL) Model

Popular Opinion Leaders

Present in all communities. Usually respected, well-informed, and trusted members of a social group

The Popular Opinion Leader Model *

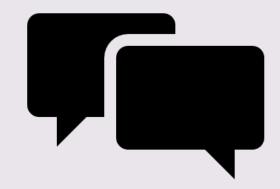
 A community-level intervention designed to influence norms, behaviors, intentions and prompt actions in a specific community

*developed by CDC for community prevention studies

How does a POL Influence Their Community?

- Social Network- a set of individuals or organizations who share common interests
- POLs can spread information about health and scientific research through their social networks

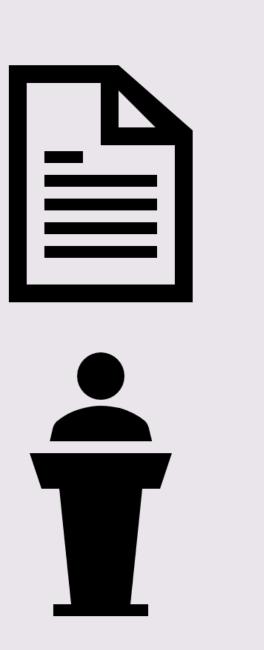






How do POLs Help Their Communities?

- By spreading information, POLs help to...
 - Increase awareness and understanding of lupus in a community
 - Help lupus patients reach specialists to help care for their lupus
 - Spread positive messages about science-based research and clinical trials
 - Build partnerships between researchers and the surrounding community



How Do POLs Spread Information?

- POLs spread the information they know by speaking with communities, congregations, and their own social networks
- Participate in round-table discussions or community forums
- Conduct surveys or ask others about their knowledge of lupus, clinical trials, and healthcare, and spread the information they know
- Give out fact sheets, info-cards, or other tools as "conversation starters" and to remind people of the information they discussed



How is a POL's Success Measured?

- The POL model is often used in partnership with academic centers
- POL participation in studies is just as valued as professional input
- POLs record who they've spoken with and observations about meetings
- POL success if measured by the number of people they are able to engage and persuade with the intended message
- POLs demonstrate their influence by changing health seeking norms, in this case increasing the understanding of lupus clinical trials in their communities.

Summary

Popular Opinion Leaders

- A trusted person in their community who is able to spread information through their social network
- POLs can help spread information about lupus, clinical trials, and healthcare
- POLs help strengthen researcher-community partnerships



QUESTIONS? THANK YOU!

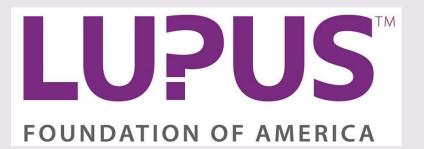
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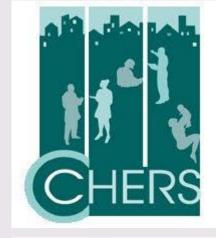


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Women of Courage Lupus Support Group







U.S. Department of Health and Human Services Office of Minority Health