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FORUM



A Guide to Discussing **Lupus Clinical Trials** With Your Doctor





Discussing Clinical Trials with Your Doctor

Introduction: Why Discuss Clinical Trials?

Why do we need Clinical Trials?

Clinical trials are an essential step in advancing medical treatments. They help researchers determine if treatments are safe and effective for specific groups, including Black people, who are often underrepresented in lupus research.

Why it matters for you:

Talking with your doctor about clinical trials can help you make informed decisions about your health. It also provides access to potential treatments that might not yet be widely available. It's a way to take control of your health and explore new possibilities.



Preparing for the Conversation



Learn the Basics

Start by learning what clinical trials are and how they work. Knowing what to expect will help you feel more confident in your discussion.



Think About Your Goals

Consider what you want to achieve through participating in a clinical trial. Is it access to new treatments, contributing to lupus research, or managing your lupus symptoms better.



Write Down Your Questions

Make a list of questions to ask your doctor. This will help you fully understand how a clinical trial works and how it could affect you.

Key Questions to Ask Your Doctor

1

Am I a Good Fit?

- Am I eligible for any clinical trials related to lupus?
- Do my current health conditions and lupus symptoms match any trials you know about?
- How do I start if I'm interested?

2

Key Questions to Ask

- What is the goal of this trial, and how could it impact lupus treatment options?
- How could it improve lupus treatments?
- Have these trials been run in the past or are they new?

3

What are the Risks and Benefits?

- What are the possible risks, side effects, and benefits of participating?
- Will this trial affect my current lupus treatments?

4

What are the Trial Commitments?

- What will I need to do during the trial?
- How often will I have to go to appointments or tests?
- Will I need to take time off work, and if so, will the trial cover travel or other costs?



Staying Safe During a Trial



Safety Checks

Every clinical trial is reviewed by experts, also known as Institutional Review Boards (IRBs), to make sure it's safe and fair for participants. These experts keep track of safety throughout the trial.



Informed Consent

Before joining a trial, you will go through a process called informed consent. The trial team will explain everything about the study including potential risks and benefits, so you can make an informed decision.



Your Rights as a Participant

You can leave a trial at any point. You also have the right to ask questions at any time and receive information about your treatment throughout the study.

What Happens If You Join a Trial?

Treatment and Monitoring

During a clinical trial, doctors will **closely check your health** with regular visits and tests.

Possible Benefits

You may receive new lupus treatments that aren't yet available to the public. This could give you access to options you would have through standard treatments. Supporting lupus research and sharing your story helps future generations live healthier lives. Your involvement advances science, improves care, and brings us closer to a cure. By educating and uplifting your community, you create a stronger, more empowered future for those with lupus.

Making Your Decision

1 Think About Your Goals

Does joining a clinical trial fit with what you want for your health? For example, do you want to better manage your lupus symptoms or contribute to research that could benefit other Black people?

2 Get a Second Opinion

Don't hesitate to ask another doctor for advice. It's important to feel confident and comfortable in your decision.

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