SCD C.A.R.E.S. Consortium

Collaboration of Advocates for Research, Education and Science

An initiative of the Sickle Cell Disease Association of America

THE PATH TO PROGRESS:

Olivia's Clinical Trial Journey

MEET OLIVIA! She's heard a lot about how clinical trials can help people with sickle cell disease like her, but she's not sure where to start. Follow her journey to learn about what it's like to participate in a clinical trial.

STEP 1. Learn more about clinical trials

Olivia is excited about the potential to access new medications and therapies that aren't on the market yet, but she's also nervous. She decides to do some research. She learns patient safety is the biggest priority for today's researchers. Most clinical trials cannot begin recruiting until approved by an International Review Board (IRB), an objective party that monitors clinical research safety. Olivia considers the layers of safeguards built into the clinical trial process and decides to keep exploring her options.

STEP 2. Find a nearby clinical trial

Olivia is ready to take the next step and find a clinical trial near her. Using the Sickle Cell Disease Association of America's Trial Finder (bit.ly/SCDAA-trialfinder), she enters her location, age, how far she is willing to travel and details about her treatment and diagnosis. The trial finder matches her with research opportunities she is eligible for. She reads about the studies and contacts researchers to learn more.

STEP 3. Make a decision

The researchers connect with Olivia and share more information about their studies. She makes notes and thinks about which trial she is the most interested in. She discusses the studies with her physician and caregiver. Her physician evaluates the options and makes recommendations. Together, Olivia, her physician and caregiver develop a list of questions to ask the researchers about treatments, tests, risks, side effects and more. Once she gets her answers, a trial stands out and she discusses it with her loved ones and decides to participate.

STEP 4. Start the trial

Before Olivia begins receiving treatments or participating in the study, she must sign the informed consent. This document explains the trial's purpose, structure and other important information. She reads the consent papers carefully and discusses her questions and concerns with her physician and the researchers, and her caregiver. Once she's ready, she signs the informed consent papers and begins the trial!

STEP 5. Progress through trial safely

Olivia's clinical trial is set to run for a few months. There are lots of opportunities for her to ask questions about her care, and she feels comfortable knowing she can stop participating at any time. Her health is closely monitored, and she continues to see her physician for regular appointments as well as keep her mental health in check. Before long, Olivia has her final treatment.

STEP 6. Make a lasting difference

When the trial is over, Olivia feels proud for participating. She knows that she is making a difference. **Today's lifechanging sickle cell disease treatments would not exist without clinical trials.**

Olivia's willingness to volunteer takes us one step further on the path to progress.

WILL YOU JOIN HER?

Helpful Resources & Links:

- SCDAA's Clinical Trial Finder: bit.ly/SCDAA-trialfinder
- ASH Research Collaborative: ashresearchcollaborative.org/s/
- The William E. Proudford Fund: wepsicklecell.org/clinical-studies
- Cure Sickle Cell Initiative: curesickle.org
- SCD C.A.R.E.S. Consortium: sicklecelldisease.org/scdcares

SCD C.A.R.E.S. Members:

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This information is brought to you by the SCD C.A.R.E.S. (Collaboration of Advocates for Research, Education and Science) Consortium, an initiative of the Sickle Cell Disease Association of America. The mission of this initiative is to raise awareness about the importance of clinical trials and why it's beneficial for sickle cell warriors to participate in them.

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