



ASH RESEARCH COLLABORATIVE

Accelerating Progress
in Hematology



Sickle Cell Disease Clinical Trials Network

The ASH Research Collaborative (ASH RC) was established by the American Society of Hematology in 2018 to foster collaborative partnerships to accelerate progress in hematology, with the goal of improving the lives of people affected by blood diseases.

At the core of the ASH Research Collaborative is its Data Hub, a technology platform that facilitates the exchange of information by aggregating research-grade data on hematologic diseases in a central place for the purposes of scientific inquiry. The Sickle Cell Disease (SCD) Clinical Trials Network (CTN) is an ASH RC initiative launched with a mission of improving outcomes for individuals with SCD by expediting SCD therapy development and facilitating innovation in clinical trial research.

The Need

While there are currently only two U.S. Food and Drug Administration (FDA)-approved drugs to treat the disease, there is a robust SCD drug development pipeline poised to drive demand for SCD clinical trials to a new level, providing a prime opportunity to advance treatment and care of those affected by SCD.

At the same time, there are many challenges in conducting clinical trials for SCD, including a shortage of primary investigators, clinical trial sites, and enrolled patients; lack of access to a centralized data repository;

poor coordination among sites; and flawed study designs. In addition, the voice of the patient has been largely absent in decisions about clinical trials in SCD, which has led to failures in patient enrollment and support.

The Vision

Through patient engagement and optimized clinical trial execution, the CTN Network will help bring new and more effective therapies to individuals with SCD.

We are seeking clinical research sites at institutions interested in joining this network of stakeholders with a shared commitment to:

- Forging new relationships with patients to increase their understanding of clinical trials and trust in SCD researchers;
- Eliminating inefficiencies through the use of a centralized data repository (the ASH RC Data Hub) and institutional review board; and,
- Focusing on the research opportunities that hold the most promise for patients.



The Network will promote quality, patient safety, and efficiency in SCD clinical trials by centralizing functions and sharing best practices. While traditional responsibilities for running a clinical trial will remain with the participating sites and industry, the Network's activities will address many of the common barriers faced in clinical trials research:

- Patient engagement/education/recruitment;
- Matching sponsors with trial sites; and
- Ensuring an efficient coordinated approach to clinical trials research.

Get Involved!

To learn more about the benefits and requirements for becoming a Network trial site:

- Visit our website at www.ashresearchcollaborative.com/network.

To apply to become a Network site, answer our request for proposals. Please note:

- Letters of intent are due January 31, 2019.
- Invited applicants will have full proposals due in Spring 2019.
- Selected sites will then undergo on-site evaluations.

Interested in volunteer opportunities related to the Network?

- Contact SCD-CTN@ashresearchcollaborative.org



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