

May 5, 2023

Minnesota Department of Health
Health Promotion and Chronic Disease Division
P.O. Box 64882
St. Paul, MN 55164-0882

Attention: Jay Desai

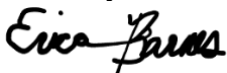
Dear Dr. Desai:

As the Executive Director for the Minnesota Rare Disease Advisory Council, a founder of a non-profit focused on raising awareness for rare diseases, and the parent of a child who was diagnosed with a rare disease (metachromatic leukodystrophy), I am honored to write a letter of support for Minnesota Department of Health's application for the *Sickle Cell Data Collection Program* grant (CDC-RFA-DD-23-0002).

Robust and comprehensive data collection is critical to improved care for rare diseases like sickle cell. This is a significant opportunity for the Minnesota Department of Health, the Minnesota Sickle Cell Collaborative, other stakeholders, and the community to collaborate to implement a statewide SCD surveillance system within Minnesota. In order to inform decision-makers and obtain resources to address the need for comprehensive SCD care across the lifespan, we need a foundation of population-level SCD data.

This letter confirms my commitment to support this project. I value our collaboration and I look forward to continuing to be a member of the Sickle Cell Data Collection Multidisciplinary Team. My time and expertise on this team will be in-kind. Improving the lives of individuals and families living with SCD, decreasing racial disparities, and advocating for support and resources for SCD is a priority issue for Minnesota. I look forward to the opportunity for families and the community to be involved in this exciting project.

Sincerely,



Erica Barnes, M.A, CCC-SLP
Executive Director