



*Sickle Cell Disease Association of America, Michigan Chapter, Inc.*

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ISSUED BY THE SICKLE CELL DISEASE ASSOCIATION OF AMERICA MICHIGAN CHAPTER

# REQUEST FOR PROPOSALS

CONTRACT FOR LOBBYIST SERVICES

January 2023

## **Request for Proposals (RFP) for State Legislative Lobbyist Services for the Sickle Cell Disease Association of America Michigan Chapter**

Under the direction of the CEO and Medical Director in concert with the Board of Directors, and SCD stakeholders in determining SCDAAMI's policy platform and priorities, SCDAAMI seeks to retain the services of a lobbyist to address matters in which professional assistance before the Michigan State Legislature, individual State Legislators, the Governor's office, and other state agencies is needed. This would be a contractual position reporting directly to the CEO.

### **ABOUT THE SCDAAMI**

The SCDAAMI has provided quality services to the sickle cell community in the State of Michigan. Founded in 1971 by Dr. Charles F. Whitten, who was one of the founders of the national organization. We are a source of trusted, reliable information, support, and resources for individuals with sickle cell disease and their families.

Our mission is:

- To maximize the quality of life for individuals living with sickle cell disease.
- To enable individuals of childbearing age with sickle cell trait to make informed decisions with respect to family planning.
- To provide education and testing to the general public.
- To serve as the coordinating center for newborn screening for hemoglobinopathies for the Michigan

Department of Health and Human Services

The SCDAAMI addresses sickle cell disease across the lifespan. Our statewide program currently employs six patient advocates/community health workers (CHWs) strategically placed in areas with the highest rates of sickle cell disease – Detroit/Ann Arbor, Lansing/Jackson, Flint/Saginaw, Benton Harbor/Kalamazoo, and Grand Rapids/ Muskegon. Patient advocates provide support services and care coordination for patients of all ages.

Through a subcontract with the Children's Hospital of Michigan's (CHM) Comprehensive Sickle Cell Clinic, additional clinical and psychosocial support services are provided for more than 700 children with sickle cell disease and their families in the Detroit metropolitan area.

### **ABOUT THE SICKLE CELL DISEASE**

Sickle Cell Disease (SCD) is the most common genetic disorder in the United States. In the US it is commonly seen in African Americans and Latin Americans however it is also common amongst those whose ancestors came from sub-Saharan Africa, Spanish-speaking regions in the Western Hemisphere, Saudi Arabia, India, and Mediterranean countries such as Turkey, Greece, and Italy. Every child born in the U.S. is tested for SCD at birth. Approximately 3,000 individuals with SCD live in Michigan with over 1500 being concentrated in the Detroit metropolitan area. While SCD affects each individual uniquely, the most common visible presentation is unpredictable, excruciating pain. However, the condition's less visible complications of chronic anemia causing

organ damage are silent, but life-shortening ramifications suffered by every individual. . Most children with SCD survive into adulthood; however, access to adult sickle cell care is poor resulting in increased acute care utilization and disjointed care delivery. In fact, there is a peak in mortality at the time of transition from pediatric to adult care. While there is no universal cure, proper treatment can help to mitigate symptoms, improve the quality of life and extend the lifespan of this historically neglected patient population.

### **Scope of Services**

CONSULTANT will provide SERVICES related to the CLIENT's advocacy and public policy strategies as directed by SCDAAMI including:

- Provide lobbying, advisory services and representation to state and local government bodies, agencies, departments, offices at the direction of SCDAAM-CEO.
- Review, analyze and report on relevant existing and proposed state of Michigan policies, programs that affect SCDAAM-CEO.
- Lead in securing sponsors for bills, codes, resolutions, amendments and/or any other regulation as necessary to accomplish SCDAAM-CEO's legislative and policy goals.
- Effectively communicate SCDAAM-CEO's legislative priorities and issues to members of Michigan State government entities;

Identify any areas of potential concern or opportunity for obtaining passage of SCDAAM-CEO's legislative priorities and other matters which may arise.

- Arrange and upon request, coordinate appointments/meetings between SCDAAM-CEO and appropriate state officials, legislators, stakeholders and partners.
- Attend team strategy meetings, legislative committee meetings, briefings, and hearings concerning matters assigned that may potentially impact SCDAAM-CEO.
- Consult with CEO regarding any legislative or executive matter which may impact SCDAAM-CEO and take any necessary action to address it.
- Submit written reports recording consultant activities and progress as to legislative priorities, and other issues as requested by CEO.
- Consultant will comply with all federal, state, and local laws, codes, ordinances, rules and regulations in performing his duties, responsibilities, and obligations related to the agreement.
- Build relationships and contact individuals and groups with similar interests to SCDAAM-CEO and encourage them to reach out to legislators on priority bills/policies.
- Testify and join CEO at public hearings as needed to enlist support for SCDAAM-CEO interests.

- Attend and represent the SCDAAM-MI at relevant meetings, hearings, and discussions of priority legislation.
- Review the legislative policy statements adopted by other local government lobbying groups, related organizations and associations to identify issues that may either positively or negatively affect SCDAAM-MI.
- Develop and evaluate strategies for the support, opposition, or amendment of pending legislation introduced in Michigan's Senate and House of Representatives.
- Appear and testify before state agency hearings, inclusive of relevant Boards and Commissions, rule-making proceedings and other administrative agencies as required, to promote, oppose, and seek passage of pertinent policies.
- Grow relationships and collaborate with opinion leaders, media and various parties involved with SCDAAM-MI programs.

### **Term of Contract**

To be determined

Please submit proposals by email to Dr. Wanda Whitten-Shurney [shurneyw@sdaami.org](mailto:shurneyw@sdaami.org) no later than February 8, 2023

If you do not receive this confirmation of receipt of your proposal within 48 hours, please contact SCDAAMI at (313) 864-4406.