

2018-2019 Community Report

48 YEARS OF IMPROVING LIVES



SCDAA-MI'S work addresses emotional, financial, social, and medical issues to help meet the biopsychosocial needs of those who rely on our services. Utilizing both innovation and best practices, the agency has been dedicated to improving the todays and tomorrows of people living with sickle cell since our founding in 1971.

Newborn Screening



57 Michigan newborns were diagnosed with sickle cell in 2018-19 through our coordinating efforts on behalf of the Michigan Department of Health and Human Services.

Nearly **700 children** and families were cared for through **3,116 visits** at the Comprehensive Sickle Cell Clinic at Children's Hospital of Michigan. **276 psychosocial assessments** were also completed.

Summer Camp

25 children with sickle cell attended North Star Reach Camp free of charge in 2019.

Of the 24 who completed their post-survey, **100%** enjoyed camp and made new friends. **22/24** campers said they'd go again.

Education & Career Counseling

We provided future-focused counseling to **121 clients** (numbers reflect multiple needs): **108** for educational needs, **67** for career guidance, and **57** for job assistance, including SSI disability transition and workplace accommodations.



Our longtime partnership with MRS continues to provide our college students with stipends toward books, travel home during breaks, and other needs.

Community Health & Social Work Services

Our staff of Community Health Workers and Patient Advocates helped identify and resolve over **365 human services challenges** that present barriers for our clients and/or their families.



These included medical care, transportation, emergency assistance, basic needs such as food and housing, and other aid.



Dr. Shurney's Speaking Highlights

- Atlanta Sickle Cell Consortium
- Congressional Black Caucus (Lansing)
- New Harvest Christian Center
- Millington Town Hall (Saginaw)
- SCDAA Nat'l Convention (Baltimore)
- WSU Women's Day Celebration
- Mt. Vernon Baptist Church
- Council of Baptist Pastors
- 7+ Federally Qualified Health Ctrs: incl. Detroit, Muskegon, and Lansing

Legislative Action



SCDAA-MI staff and sickle cell advocates attended **SCDAA's Lobby Day** and **Rare Disease Week**, joining hundreds of other patient activists from across the country.

Staff and advocates also met with local legislators to seek support for **The Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2018**. SCDAA-MI joined the Health Can't Wait Coalition's push for passage of **SB612 to change restrictions around insurance pre-authorization and step requirements**.

Fundraising

The Cynthia Coles Circle + 550 supporters at the 2019 Sickle Cell Matters Walk + our World Sickle Cell Day T-Shirt campaign equaled our best event year to-date, **raising nearly \$70k**.

In Memoriam

Our office is aware of **10 sickle cell Warriors who lost their lives** due to complications of the disease between Oct. 1, 2018 and Sept. 30, 2019. We offer our heartfelt condolences to their loved ones. **Our work continues** for them, everyone we've lost, and everyone still battling.



Community Education

91 health fairs/displays/exhibits.
39 presentations **reached more than 1,500 people** through educational presentations.