Sickle Cell Data Collection Program Policy Brief: Newborn Screening Follow-up in Georgia

January 2026

Sickle cell disease clinicians, patient advocates, and family members in Georgia identified long-term newborn screening follow-up as a priority area for policy improvement, with the goal of fostering early referral to hematology care for infants diagnosed with sickle cell disease and increasing access to timely preventive care services.

The Georgia Sickle Cell Data Collection Program aims to improve the quality of life, life expectancy, and health of individuals with sickle cell disease through the collection and use of longitudinal surveillance data. Learn more here.

Evidence of Gaps in Care for People Diagnosed With Sickle Cell Disease

The Georgia Sickle Cell Data Collection Program* uses data to inform policy and practice changes. Analysis reveals:

Preventive care can be improved.
Common quality measures for sickle cell disease care are below recommended levels.

- From 2008 through 2019, for Georgia children with sickle cell disease:
  - Up-to-date immunization rates for the primary series at 24 months were 58% and at 35 months were 66%, compared to children with sickle cell trait (56% at 24 months and 62% at 35 months); and
  - 82% of Georgia children with sickle cell disease completed the pneumococcal vaccine series by 35 months.†
- From 2010 through 2019, for individuals with hemoglobin S/S or S/β-zero thalassemia:
  - 15.5% of patients aged 3 months to 5 years were dispensed antibiotic prophylaxis for at least 300 days within each measurement year.
  - 52.7% of patients aged 2 to 15 years received at least one transcranial Doppler ultrasound within each measurement year to assess stroke risk.
  - In 2019, 37% of children filled at least three prescriptions for hydroxyurea (medication possession ratio: 23%).‡

Many barriers to care exist.
Universal newborn screening, combined with improvements in preventive care, have led to better survival rates for individuals with sickle cell disease, but affected infants and their families still face barriers that result in suboptimal and delayed sickle cell care.

- Nationally, there is significant variation across states in both the initial reporting of screening results to families and establishing sickle cell disease care.§
- Specific barriers in Georgia include:

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- **Provider access barriers**. Thirteen percent of Medicaid-enrolled pediatric patients with sickle cell disease had no hematology visit from 2016 to 2018.[**]
- **Socioeconomic barriers**. Two-thirds of newborns with sickle cell disease reside in counties with high or very high social vulnerability.[††]
- **Insurance barriers**. Of the 471 children with sickle cell disease identified through the newborn screening program (2015 to 2017), 45% of those ever covered by Medicaid experienced disrupted coverage or lost Medicaid coverage during their first three years.

Long-Term Lessons Learned From Other States

Colorado

Centralized Statewide Follow-Up

The Colorado Sickle Cell Center, under contract with the Colorado Department of Public Health and Environment (CDPHE), manages newborn screening follow-up for all infants in Colorado and Wyoming with sickle cell disease or other hemoglobinopathies.

Data Infrastructure

The Colorado long-term, follow-up program tracks all children with disorders identified on newborn screening, and alerts providers and public health staff at CDPHE if a child has not been seen by the appropriate care provider according to the recommended schedule or if laboratory testing has not been performed. Data collected and reported by clinicians in the Epic Healthy Planet dashboard include demographics; insurance status; visit status; date of most recent transcranial Doppler ultrasound; status for meningococcal, influenza, and pneumococcal vaccines; and whether the child has been prescribed hydroxyurea, penicillin, or erythromycin. Currently, community-based organizations are not granted access to the data dashboard.

Florida

Referral Center-Based Follow-Up

The Florida Department of Health contracts with 11 referral centers to provide newborn screening follow-up. Each referral center maintains its own tracking system (using spreadsheets) to provide follow-up services. Referral centers hire community health workers to establish and maintain care for hard-to-reach families.

New Sickle Cell Registry

The Florida Sickle Cell Registry, established in Florida statute §383.147(2)(a), includes newborn screening results for those identified as having sickle cell disease or trait. The purpose of the registry is to monitor trends in diagnosis, treatment, and health care access for those living with sickle cell disease or trait in Florida.

Michigan

Community-Based Organization Follow-Up

Since 1987, Michigan's Department of Health and Human Services (MDHHS) has partnered exclusively with the Sickle Cell Disease Association of America Michigan Chapter (SCDAA–MI) to conduct follow-up via patient advocates who provide education, ensuring newborns are connected to care and receive follow-up services and timely preventive care, such as antibiotic prophylaxis. This has reduced the number of infants lost to follow-up.

Comprehensive Data Integration

MDHHS manages the Michigan Care Improvement Registry, which performs long-term follow-up and tracks immunizations and treatment compliance for nine conditions, including sickle cell disease. MDHHS collaborated with SCDAA-MI to add patient-reported health status assessments to Michigan's Sickle Cell Data Collection Program.

North Carolina

Legislatively Mandated Program

In 1973, the North Carolina Department of Health and Human Services (NCDHHS), established the North Carolina Sickle Cell Syndrome Program (NCSSP), a legislatively mandated program, to provide newborn screening follow-up and comprehensive services to individuals and their families affected by sickle cell disease. It is supported by nine regional sickle cell educator counselors and contracts with community-based organizations and six comprehensive sickle cell medical centers.

Holistic Long-Term Care Model

NCSSP manages a database to track families who received a positive screening result and opt in to be tracked long-term. The follow-up data is accessible to NCSSP and all its partners (community-based organizations, clinics, educator counselors, and NCDHHS staff). Long-term follow-up involves trust building, annual needs assessments, and wraparound services, supported by a mix of state, federal, and Medicaid funding. The quality-improvement program for newborn screening follow-up is funded by a grant from the Health Resources and Services Administration.

Next Steps for Newborn Screening in Georgia

Informational interviews with other states identified that tracking individuals living with sickle cell disease beyond the newborn period, well into transition ages and adulthood, yields overall positive health outcomes. While there is variation in the newborn screening follow-up programs across states, a coordinated and multi-institutional commitment for follow-up is essential for successful statewide sickle cell disease long-term follow-up.

To establish a long-term follow-up program for sickle cell disease in Georgia, additional resources are needed. Resources can support the development of a formalized data-tracking system that imports patient information from electronic health records and enables real-time sharing of patient data across institutions, key stakeholders (including the Sickle Cell Foundation of Georgia), and a broader network of adult sickle cell disease providers across the state. This can be possible through investment from multiple sources, including legislative funding; the state public health system; and state, federal, and philanthropic grants.

Action to Date

The Georgia Newborn Screening Advisory Committee is actively involved in advocating for a statewide, long-term follow-up program for sickle cell disease. Due to state-level funding constraints, the advisory committee recommended the sickle cell disease follow-up programs at Children's Healthcare of Atlanta and Augusta University (AU) explore alternative funding mechanisms to support the proposed work. To date, Children's has made progress in developing an Epic dashboard, similar to Colorado and Connecticut, through foundation funding from the Abraham J. & Phyllis Katz Foundation (2025).‡‡ Similarly, AU and the Georgia Sickle Cell Data Collection Program jointly obtained an internal grant from Georgia State University to fund the implementation of an Epic-integrated data dashboard for tracking newborns with sickle cell disease at AU (2025). While funding for these Epic-based data dashboards is a key first step, the determination of the eventual ownership of long-term follow-up in the state is paramount to ensuring statewide sickle cell disease tracking and seamless communication between the Department of Public Health, clinical centers, and community-based organizations. In other states, this role is largely undertaken by the public health department that is charged with managing the newborn screening long-term follow-up program.

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