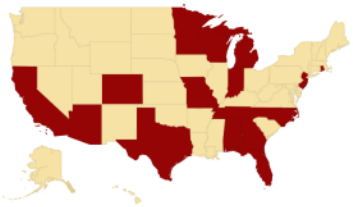
FISCAL YEAR (FY) 2025 FEDERAL REQUESTS FOR SICKLE CELL

Co-Sponsor Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2023 (H.R.3884 / S.1852)

- **Authorize the appropriations of $8.205 million** each year from 2024 through 2028 for the Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA) to conduct research, surveillance, prevention, and treatment of sickle cell disease and related blood disorders.
- **Reauthorize** the Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2018 (PL 115-327).
- **Continue funding** for the HRSA Demonstration Programs.

Appropriate $25 Million for the CDC Sickle Disease Data Collection Program



- **Appropriate $25 million for Centers for Disease Control and Prevention (CDC) Sickle Cell Data Collection (SCDC) Program.** The SCDC program gathers health information from multiple sources to determine how many people live with the disease in a particular state.
- The SCDC currently covers 16 states which are home to approximately 50% of the SCD Population in the USA with plans to expand.
- The goals of the SCDC include learning where people with SCD live, gathering information on the transition from pediatric care to adult care, gathering demographic information, and much more.
- Data collection is necessary to improve national incidence and prevalence data; better identify health disparities; and evaluate strategies to improve quality of life and lower costs associated with treating the population.

Appropriate $15 Million for Programs under the HRSA Sickle Cell Disease Treatment Act

- **Appropriate $8.205 million to the Sickle Cell Disease Treatment Demonstration Program (SCDTDP).** SCDTDP is a HRSA grant program with the following goals:
  - Increase the number of clinicians or health professionals knowledgeable about the care of SCD.
  - Improve the quality of care provided to individuals with SCD, care coordination with other providers.
  - Develop best practices for coordination of services during pediatric to adult transition.
- **Appropriate $7 Million to The Sickle Cell Disease Newborn Screening Follow-up Program (FP) through the Special Project of Regional And National Districts.**
  - Fund sickle cell disease activities performed by community-based organizations.
  - Provide education for people living with SCD, families, and clinicians.
  - Continued program efforts will accelerate the identification and implementation of best practices and procedures for SCD care.

Encourage your state Medicaid Director to participate in the Cell and Gene Therapy (CGT) Access Model.

- The CGT Access Model will focus on treatments for people living with sickle cell disease (SCD). **Letters of Intent (LOIs) for states are due April 1, 2024.**
- The CGT Access Model aims to improve the lives of people with Medicaid by increasing access to potentially transformative treatments.
- Cell and gene therapies have high upfront costs but have the potential to reduce health care spending over time by addressing the underlying causes of disease, reducing the severity of illness, and reducing health care utilization.
- The CGT Access Model is a strategy to increase equitable solutions for individuals with SCD and their families and reduce health disparities.

SICK CELLS

sickle cell community consortium