The Honorable Robert F. Kennedy Jr.
Secretary
United States Department of Health and Human Services
200 Independence Avenue, S.W.
Washington, D.C. 20201

Dear Secretary Kennedy,

We, the undersigned organizations and advocates, write to express urgent concern regarding the potential suspension of the Centers for Disease Control and Prevention's (CDC) Sickle Cell Data Collection program and the termination the Health Research and Services Administration (HRSA) Advisory Committee on Heritable Disorders in Newborns and Children amid the ongoing reorganization of the U.S. Department of Health and Human Services (HHS).

As community leaders, researchers, providers, and most important, families living with SCD dedicated to improving the lives of those living with Sickle Cell Disease (SCD), we urge HHS to ensure that the Sickle Cell Data Collection program, its key personnel with historical knowledge of the programs and community it serves, and the HRSA Advisory Committee on Heritable Disorders in Newborns and Children are protected and preserved.

**CDC: Sickle Cell Data Collection Program (SCDC)**

The SCDC program is the only national public health surveillance initiative solely focused on individuals living with SCD. This program received its first congressional appropriation in 2019, under the first Trump administration. Because of those funds and continued congressional funding, the program has expanded from two states to 16 states. This was all made possible through community engagement, congressional support, and the action of the trusted federal champions within HHS and the previous Trump administration.

The program collects, analyzes, and disseminates essential data on SCD prevalence, care patterns, health outcomes, and mortality—data that is not otherwise systematically gathered on a national scale. This data empowers health systems, policymakers, researchers, and SCD community-based organizations (CBOs) to close care gaps, address disparities, and drive innovations that save lives. The SCDC program partners with local health departments and community members to ensure that every single person with SCD is counted. Their work offers honest, unbiased science. The personnel that run the programs have gained the SCD community's public trust. The data from the SCDC program drives decisions made for all federal and state programs including programs providing health services.

For example, in Michigan data from the SCDC program directly informed the expansion of Title V benefits to include adults with SCD, helping the state identify and reach eligible individuals who were previously overlooked. Hundreds are now enrolled in a program that provides much-needed health services, thanks to strategic data use and interagency collaboration. This level of insight and impact would not be possible without the SCDC program's unique ability to integrate data from newborn screenings, Medicaid, clinics, and hospital systems.

At the state level, last week (April 2, 2025) the General Assembly of North Carolina introduced House Bill 663 entitled Expand Sickle Cell Disease Programs and Services. The Assembly used data directly from the SCDC program. Data from the SCDC program showed a 25 percent increase in what the state previously estimated as the number of people living with sickle cell disease. This resulted in the request of additional state funds to ensure that essential services are available statewide to support the growing number of North Carolinians affected by sickle cell disease.

At a federal level, the SCDC program worked with CMS, the White House and Office of the Assistant Secretary to publish its first-ever Medicaid and CHIP Sickle Cell Disease Report. This report was unveiled at a historic First Lady Roundtable on Improving the Lives of Americans Living with Sickle Cell Disease in 2020.

The current Centers for Medicaid and Medicare Innovation (CMMI), Cell and Gene Therapy (CGT) Access Model relies on the SCDC program to identify where all individuals with SCD seek care and who are eligible for innovative and emerging therapies. The program makes it possible to achieve the White House's goal to champion accelerated medical breakthroughs in genetic treatment for sickle cell disease.

The loss—or even temporary disruption—of this program, including termination of staff, would undermine more than a decade of progress in building a national infrastructure for SCD surveillance and shatter rapport, trust, transparency, and confidence in HHS. The suspension of this program will halt all current and new federal, state, and local SCD programs that rely on this data and its stewards of unbiased science to make sound decision making.

**HRSA: Advisory Committee on Heritable Disorders in Newborns and Children**

We are equally concerned by the recent termination of HRSA's Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC). This advisory committee played a vital role in evaluating and recommending conditions—including SCD—for inclusion in the Recommended Uniform Screening Panel (RUSP). The ACHDNC served as a trusted, evidence-based advisory body that ensured that newborn screening policy reflected the latest science and the needs of affected communities. Its absence creates a critical gap in federal oversight and coordination, particularly for conditions like SCD that require early intervention to improve outcomes and save lives. We urge HHS to prioritize the reestablishment of this committee or a comparable mechanism to uphold the integrity and equity of newborn screening in the United States.

**A Call for Continued Partnership**

Under President Trump's leadership during his first term, HHS took historic steps to expand access to care and treatment for Americans with SCD. These efforts included funding the National Academies of Sciences, Engineering, and Medicine (NASEM) to develop a strategic plan and blueprint for action on SCD, a landmark publication that outlined key federal policy steps. Additionally, the Trump Administration improved the CDC's SCDC program, worked with Congress to enact the Sickle Cell Disease and Other Heritable Blood Disorders Research,

Surveillance, Prevention, and Treatment Act, and supported gene therapy research that has brought curative treatments closer to FDA approval. These efforts laid a strong foundation for improving the quality of life for those living with SCD.

The undersigned organizations urge you to build upon this progress by protecting and preserving the very programs that have made meaningful change possible. Ensuring the continuity of the SCDC program and reinstating key advisory mechanisms like the Advisory Committee on Heritable Disorders in Newborns and Children will demonstrate HHS's continued commitment to improving outcomes and advancing solutions for individuals and families impacted by Sickle Cell Disease. Now is the time to accelerate—not retreat from—our shared goal of delivering better care, treatment, and support for all people living with SCD in the United States.

Signed in alphabetical order:

Advancing Sickle Cell Advocacy Project Inc
American Society of Hematology
Association for Sickle Cell Lower Chattahoochee Region, Inc.
Axis Advocates
Ayana's Hope Cells
Bridging the Gap Adult Sickle Cell Disease Foundation of Nevada
Conquering The Curve, Inc.
Cortney Vega S.A. Foundation
Dre365
Foundation for Sickle Cell Disease Research
Freedom Virginia
JAYJ Foundation for Women and Children
Kids Conquering Sickle Cell Disease Foundation
Kincaid's Kindred Spirits, Inc
Massachusetts Sickle Cell Association
May5Foundation
MTS Sickle Cell Foundation, Inc.
Northeast Louisiana Sickle Cell Anemia Foundation
Ohio Sickle Cell and Health Association
Paterson Community Health Center
RedMoon Project
Scott Center for Observation Treatment and Transition
Shak's Hope Inc
Shakevia's Sickle Cell Anemia Foundation Inc
Sick Cells
Sickle Cell 101
Sickle Cell Advocates of Rochester
Sickle Cell Association (St. Louis, MO)
Sickle Cell Association of Kentuckiana
Sickle Cell Awareness 365

Sickle Cell Coalition of Maryland
Sickle Cell Consortium (SC3)
Sickle Cell Disease Association of America, St Petersburg Chapter
Sickle Cell Disease Association of America, Mobile Chapter
Sickle Cell Disease Association of America, Inc.
Sickle Cell Disease Association of America, Philadelphia/Delaware Valley Chapter
Sickle Cell Disease Foundation
Sickle Cell Disease Partnership
Sickle Cell Family & Peer Advocates of Tidewater
Sickle Cell Foundation of Georgia, Inc.
Sickle Cell Foundation of Minnesota
Sickle Cell Medical Advocacy Inc
Strong Children Wellness
The B Strong Group
The Levi Long Sickle Cell Association
The Potters Smile Inc.
The Riley Foundation for SCD
The Sickle Cell Association of New Jersey
The Sickle Cell Foundation of Tennessee
Through The Pain Inc.
University of Miami Sickle Cell Center
Uriel E. Owens Sickle Cell Disease Association of the Midwest
Virginia Sickle Cell Network
West Alabama Sickle Cell Anemia Foundation, Incorporated