February 5, 2026

Frank Bisignano
Commissioner
Social Security Administration
6401 Security Boulevard
Baltimore, MD 21235

Dear Commissioner Bisignano,

On behalf of the many organizations that work together to address the needs of the sickle cell disease community, we are reaching out to bring to your attention the major report issued in December 2025 by the National Academies of Sciences, Engineering, and Medicine (NASEM) titled, "Sickle Cell Disease in Social Security Evaluations." This report was requested by your agency and represents a comprehensive and up to date review of sickle cell disease, modern treatments, and how individuals (both adults and children) are evaluated for eligibility for Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). Representatives from our organizations are very interested in meeting with you and your staff to discuss the report's conclusions and how we can draw upon this comprehensive study to revise the adult and child Medical Listings of Impairments for Sickle Cell Disease (SCD) to accord with findings in the NASEM report; and define and establish SCD as a disabling Compassionate Allowance condition to speed disability decisions for those with severe SCD symptoms.

As you know, SCD is a chronic, lifelong condition affecting every organ system of the body. Individuals with SCD suffer daily or persistent pain, as well as acute pain crises. As the opening pages of the NASEM report note, more than 90% of individuals with SCD are Black or African American. Life expectancy at birth is 52.6 years, more than twenty years shorter than the life expectancy of the average American; and quality-adjusted life expectancy is more than thirty years shorter, itself a strong indicator of disability.

The NASEM report brought together the nation's leading hematologists and SCD experts, who made extensive findings and drew a number of overarching conclusions. Appended to our letter is a summary of what we believe are its significant findings that relate to a revision of the Medical Listings for SCD and to the establishment of a Compassionate Allowance for SCD.

We also wish to recognize and express our appreciation for the major sickle cell disease policy and funding initiatives undertaken at the Department of Health and Human Services (HHS) during President Trump's first term. During this period, HHS took several significant actions to strengthen

federal engagement on sickle cell disease, including supporting the development of a national strategy through the National Academies, expanding the Centers for Disease Control and Prevention's (CDC) data collection efforts, advancing bipartisan legislation on research and surveillance, and promoting innovation in gene-based therapies. Collectively, these actions helped establish a stronger federal framework for improving care, research, and outcomes for individuals living with sickle cell disease.

We look forward to working with you to revise the adult and child Medical Listings of Impairments for Sickle Cell Disease to accord with findings in the NASEM report; and define and establish SCD as a disabling Compassionate Allowance condition to speed disability decisions for those with severe SCD symptoms. Working together we believe that we can provide a more accurate, speedier and fairer evaluation of children and adults with SCD. Thank you for your leadership and consideration of our request.

Please contact Leslie Brady with the Sickle Cell Disease Association of America, Inc. at Lbrady@artemispolicygroup.com, Maia Laing with Sick Cells at MLaing@sickcells.org, or Jonathan Stein with Community Legal Services of Philadelphia at jstein@clsphila.org with any questions and to schedule the requested meeting.

Sincerely,

Regina Hartfield, President and CEO, Sickle Cell Disease Association of America, Inc.
Ashley Valentine, CEO, Sick Cells
Robert Negrin, MD, President, American Society of Hematology
Maria Velez, MD, President, American Society of Pediatric Hematology/Oncology
Julie Kanter, MD, President, National Alliance of Sickle Cell Centers
Lakiea Bailey, PhD, Executive Director, Sickle Cell Community Consortium
Jonathan Stein, Community Legal Services of Philadelphia
Linda Landry, Disability Law Center, Inc., Boston
Thomas Yates, Legal Council for Health Justice, Chicago

Cc: Jay Ortis, Acting Chief of Disability Adjudication
Mark Steffensen, Chief of Law, Policy, & Legislative Affairs
Nicholas Perrine, Chief Communications Officer

Attachment of Summary of Key Conclusions of NASEM's "Sickle Cell Disease in Social Security Disability Evaluations" (Dec. 2025)

Key Conclusions from "Sickle Cell Disease in Social Security Disability Evaluations" Of the National Academy of Sciences, Engineering and Medicine

1. "A large body of research shows that people living with SCD experience disability…." (p. 212).

2. Many people with SCD have a level of disease severity and significant functional limitations to qualify for disability, yet do not meet the overly restrictive Listings criteria. These criteria, which the NASEM report found do not reflect current SCD medical treatment and management practices, require use of opioid pain management, and at least three hospitalizations of at least 48 hours, each separated by 30 days apart. (Overarching Conclusion 4, pp. 9-10). These Listings criteria ignore modern pain management techniques, as the full spectrum of pain experienced daily is most often managed at home or in various outpatient care settings. (Overarching Conclusion, pp. 6-8). Specifying at least 48 hours inside the hospital as a criterion of pain severity "is not clinically meaningful"; and a required separation of 30 days between crises "is an arbitrary cut off" and "not scientifically justified." (pp. 47, 54, Conclusions 4-1. 4-2, pp. 106-107). Emergency department visits and hospitalizations "are too restrictive a measure of SCD severity." (p.60).

3. Quantifying the burden of a person's pain should not be based on frequency of health care utilization; the patient's report of pain "remains the gold standard diagnostic criterion for determining an SCD crisis." (pp. 49-50). The type of medications or interventions used to treat an acute pain crises are "too restrictive as proxies for the severity of pain or the underlying disease process." (Conclusion 3-4, p.77).

4. People with SCD may experience "complications in nearly all body systems" (p.165). Because of SCD's chronic and multisystem nature and these multiple conditions' cumulative effect that severely impacts the person's overall functioning, the current evaluation system, including Listing 7.18, does not accurately assess the cumulative burden, the additive effect of the conditions plus SCD. The complications in nearly all body systems do not have associations with other SSA Listings and may not reach the needed threshold of a particular Listing yet have a "cumulative impact on multi-organ involvement" impairing ability to work. (Overarching Conclusion 7, Conclusion 6-1, pp. 12-14, 165-166, 219-221).

5. Requiring an individual who does not meet SCD Listings 7.05 or 7.18 to "meet or equal" another body system Listing, is "unlikely to capture the full burden or severity of the disease on the individual." (pp. 220-221). People with SCD have limited access to other specialists and the complex diagnostic processes for such complications as neurocognitive, mental and behavioral disorders to document the other Listings' criteria. (Conclusion 5-3, pp.120, 124, 126). A person

with SCD may have “clinically significant chronic kidney disease without “meeting” the SSA kidney disease Listing. (p. 13).

6. Many people with SCD will not have complete and integrated medical records to document the full range of SCD-related health conditions and symptoms, due to the fractured nature of the American medical system. SSA’s adoption of SCD evaluation templates or forms would help to better capture the comprehensive information needed for an accurate evaluation under the SCD Listings. (Overarching Conclusion 7, pp. 13, 220, App. B.)

7. The childhood Listings do not include an analogue to the adult SCD Listing 7.18, itself deemed inadequate by NASEM that covers the full range of functional impacts that children with SCD may have. The inclusion of an analogous childhood Listing to Listing 7.18 would provide medical professionals and advocates with a better understanding of the information needed in evaluating cumulative burden of SCD on a child and would also help to facilitate the redetermination process for adult disability at age 18. (Overarching Conclusion 7, pp. 13-14, 219-21, 233).

8. Among the many serious functional impacts of SCD, the NASEM committee reports: numerous studies show SCD “significantly affects the ability of adults to participate fully in the workforce,” resulting in high absenteeism, presentism, reduced productivity and difficulty maintaining consistent employment. The rates referenced include: 31.9% absenteeism, 44.8% presentism, 63.7% reduction in productivity. (pp. 198-199). Thirty-two percent of people with SCD have as a result been dismissed from their jobs; people with SCD miss an average of 7 hours of work a week (p. 52). Children with SCD had “lower scores across all health-related quality-of-life domains,” (p. 184); higher rates of grade retention and absenteeism, and lower scores. (pp. 196-198. 212).