May 19, 2022

The Honorable Ron Wyden Chairman Senate Finance Committee 221 Dirksen Senate Office Building Washington, DC, 20510

The Honorable Debbie Stabenow Chair Senate Finance Subcommittee on Health Care 731 Hart Senate Office Building Washington, DC 20510 The Honorable Mike Crapo Raking Member Senate Finance Committee 239 Dirksen Senate Office Building Washington, DC 20510

The Honorable Steve Daines Ranking Member Senate Finance Subcommittee on Health Care 320 Hart Senate Office Building Washington, DC 20510

Dear Chairman Wyden, Ranking Member Crapo, Chair Stabenow, and Ranking Member Daines:

The undersigned organizations, all committed to improving outcomes for individuals with sickle cell disease (SCD), seek your leadership in marking up the Sickle Cell Disease Comprehensive Care Act (S. 3389) introduced by Senators Cory Booker and Tim Scott. Our organizations strongly demonstration program for Medicaid beneficiaries to improve acc individuals with 9Thvn.9 (([in Tc 08.25n Tcd(.)Tj)]T22n approvals of new treatments for SCD and more in the pipeline, there is no better time than now to improve the SCD community's access to state-of-the-art care.

Additionally, the proposed demonstration program addresses the priority areas highlighted in CMS' recently released action plan to address health equity. The SCD demonstration program has the capability to eliminate disparities in health care quality and access for this extremely vulnerable population, which in turn, could serve as a model for CMS' multifaceted efforts to improve health equity and eliminate disparities.

Now is the time to initiate this program. We need your leadership to advance the bill in your committee. Our organizations are committed to seeking cosponsors and working with the committees of jurisdiction to move the policy and program forward.

Please consider all of the organizations listed below as a resource and keep us apprised on how we can assist you. Thank you again for your efforts to improve the lives of individuals with this debilitating disease.

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Agios Pharmaceuticals Alpert Medical School of Brown University American Academy of Pediatrics American College of Emergency Physicians American College of Obstetricians and Gynecologists American Heart Association American Psychological Association American Public Health Association American Red Cross American Society for Clinical Pathology American Society for Reproductive Medicine American Society for Transplantation and Cellular Therapy American Society of Hematology American Society of Pediatric Hematology/Oncology American Thoracic Society ASH Research Collaborative Association of Pediatric Hematology/Oncology Nurses Association of Maternal & Child Health Programs Association of Public Health Laboratories Axis Advocacy **Beam Therapeutics** Black Women's Health Imperative bluebird bio Bridging the Gap-Adult Sickle Cell Disease Foundation of Nevada Cayenne Wellness Center | Sickle Cell Education, Support, and Advocacy **Forma Therapeutics** Foundation for Sickle Cell Disease Research **Global Blood Therapeutics** Graphite Bio Greater Boston Sickle Cell Disease Association