

April 27, 2023

The Honorable Cory Booker  
717 Senate Hart Office Building  
Washington, DC 20510

The Honorable Danny Davis  
2159 Rayburn House Office Building  
Washington, DC 20515

Dear Senator Booker and Representative Davis:

On behalf of First Focus Campaign for Children, a bipartisan children's advocacy organization dedicated to making children and families the priority in federal policy and budget decisions, we are writing to express our support for the Sickle Cell Disease Comprehensive Care Act (H.R.1672/S.904).

Sickle cell disease (SCD) is a debilitating illness that can include severe bouts of pain, stroke, and epilepsy.<sup>1</sup> Episodes of pain can last for weeks, greatly decreasing children's quality of life. SCD disproportionately impacts African American children, and one out of every 365 African-American children are born with SCD annually.<sup>2</sup> Without access to proper care, children face reduced life-expectancy and potential organ failure.

As of 2019, 3,300 children with sickle cell anemia, the most severe form of sickle cell disease, were enrolled in Medicaid.<sup>3</sup> However, of these 3,300 children, less than half received the recommended stroke screenings and many did not receive medications that ease pain brought on by SCD.<sup>4</sup> Long-term damage and decreased life expectancy is preventable, and access to adequate care helps patients lead longer lives. However, structural racism and systemic failures have created barriers to screening, treatment, and care.<sup>5</sup>

While the life expectancy of those living with SCD is lower, with proper access to care 98% of impacted children will reach adulthood.<sup>6</sup> These children are less likely to have access to a comprehensive medical team than patients with other genetic disorders, and therefore rely heavily on

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<sup>1</sup> Galadanci, Aisha A., DeBaun, Michael R., Galadanci, Najibah A. "Neurological complications in children under five years with sickle cell disease." *Neuroscience Letters*, Vol 706. July 2019. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7147490/>.

<sup>2</sup> "Data and Statistics on Sickle Cell Disease." Centers for Disease Control and Prevention. May 2, 2022. <https://www.cdc.gov/ncbddd/sicklecell/data.html>.

<sup>3</sup> "Many Children with Sickle Cell Anemia Not Receiving Lifesaving Screening and Treatment." Centers for Disease Control and Prevention. September 20, 2022. <https://www.cdc.gov/media/releases/2022/s0920-vs-sickle-cell-anemia.html>.

<sup>4</sup> Ibid.

<sup>5</sup> Ibid.

<sup>6</sup> Galadanci, Aisha A. et al. "Neurological complications in children under five years with sickle cell disease."

Medicaid for their life-saving care. The Sickle Cell Disease Comprehensive Care Act takes strides to combat the systemic racism in SCD care and ensure that these children have access to the life-saving screenings and medication that they need to lead full lives. Expanding the covered care can prevent costly emergency-room visits, strokes, and debilitating pain episodes.

We commend you for working to expand sickle cell disease care for Medicaid enrollees and provide them with the life-saving care they need. We look forward to working with you to pass the Sickle Cell Disease Comprehensive Care Act.

Sincerely

A handwritten signature in blue ink that reads "Bruce Lesley". The signature is written in a cursive style with a prominent "L" and "y".

Bruce Lesley  
President