



May 11, 2022

Re: \$30 Million Budget Request – Continued Funding for Networking California for Sickle Cell Care

Members of the California Legislature,

On behalf of the undersigned organizations, we are writing to request your support for the inclusion of \$30 million in the 2022 Budget Act allocated to the expansion of Networking California for Sickle Cell Care (“Network”). The sustained funding over the next three years will allow the state’s first and only network of specialized Sickle Cell Disease clinics to continue upon its success in expanding services and improving care for California adults living with Sickle Cell Disease.

California is home to an estimated 9,000 people living with Sickle Cell Disease, an inherited blood disorder that primarily affects African Americans and Latinos,¹ two-thirds of whom are adults who never had the opportunity to receive care from a specialty clinic or even a provider knowledgeable of the disease. In the absence of adult sickle cell centers, preventable pain crises and other complications frequently led to emergency room visits and hospitalizations at an estimated cost of \$2.4 billion annually.

In 2019, the California Legislative Black Caucus with the leadership of Assemblymember Mike Gipson (D-Carson), introduced legislation to address the root cause of these shameful statistics. [AB 1105 \(Gipson\)](#) proposed building a network of adult Sickle Cell Disease clinics throughout California, which was secured in Governor Newsom's 2019 Budget Act, and led to the creation of the Network.

In the first two years of a three-year initiative, the Network, led by the Center for Inherited Blood Disorders in partnership with the Sickle Cell Disease Foundation, surpassed its goal of initiating five Sickle Cell Disease clinics and opened 10 throughout the state. In addition to increasing the health care workforce of knowledgeable clinicians, enhancing surveillance to better track the disease and analyze impacts, and strengthening education through competitive grants, data from the two oldest clinics in the Network showed a cost savings of more than \$1 million for 28 patients due to decreased emergency room and hospital visits. Considering that data is from 2019 just as the other clinics were being established, the Network anticipates much larger savings in the years to follow.

Although California was once sorely lacking in adequate, equitable, Sickle Cell Disease care, the Golden State is now being recognized as a leader, largely in part due to the Network. Other states are even beginning to emulate the Network’s model, with Michigan recently approving \$6.7 million for a Sickle

¹ <https://3u1ssmrzuzd1aeai22lh31l-wpengine.netdna-ssl.com/wp-content/uploads/2020/09/NCSCC-Year-1-Report-Final-E-Distribution.pdf>

Cell Disease Initiative.² Recognition for California's innovations continues to grow following reports by national leaders and citations in prestigious publications such as the *National Institute for Children's Health Quality*,³ *Nature*,⁴ and *The National Academies of Sciences, Engineering, Medicine*.⁵ Now that the Network's infrastructure and staff are in place, and as patients begin to utilize the Network in much larger numbers, it's critical that sustained funding be made a priority to support this clinical network and implement workforce development statewide.

Thank you for your time and attention to this matter. Together, we hope to continue to improve the quality of life for adults living with Sickle Cell Disease in California and ensure they are neglected no more.

Sincerely,



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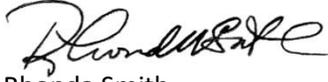
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² <https://www.midlandmpo.org/recent-news/2021/9/28/state-of-michigan-announces-bipartisan-budget-agreement>

³ https://issuu.com/nichg/docs/2021_scd_congressional_report_nichg

⁴ <https://www.nature.com/articles/d41586-021-02143-z>

⁵ <https://www.nationalacademies.org/our-work/addressing-sickle-cell-disease-a-strategic-plan-and-blueprint-for-action>



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