



March 7, 2022

The Honorable Shane E. Pendergrass
Chair, Health and Government Operations Committee
Room 241
House Office Building
Annapolis, Maryland 21401

**RE: HB 1192 – Maryland Health Care Commission - Studies of Issues Affecting
Individuals with Sickle Cell Disease**

Dear Chair Pendergrass:

The Maryland Health Care Commission (the “MHCC”) is submitting this letter of information on *HB 1192 – Maryland Health Care Commission - Studies of Issues Affecting Individuals with Sickle Cell Disease*.

House Bill 1192 (“HB 1192”) would require the MHCC to conduct three separate studies relating to sickle cell disease and treatment. The MHCC, in consultation with the Maryland Department of Health and various medical experts, clinicians, and stakeholders, to conduct studies on individuals who provide medical services in emergency departments and their knowledge of sickle cell disease, the coordination of health care for individuals with sickle cell disease who are transitioning from pediatric to adult health care in the State, and Maryland Medical Assistance Program enrollees seeking medical care for sickle cell disease outside the State. The bill also requires the Commission to provide a copy of the report to a person on request. Lastly, the Maryland Health Care Commission must report its findings and recommendations from the studies to the Senate Education, Health, and Environmental Affairs Committee and the House Health and Government Operations Committee by July 1, 2023.

In reviewing the HB 1192 and the nature of the studies we believe there needs to be more information on the burden and challenges of the disease on the community. Therefore, we suggest that there be a request for proposal (RFP) approach or grant fund approach to gather and learn scientific information about sickle cell disease, treatment, and the transitional issues related to moving from pediatric care to adult health care. Additionally, we want to point out that there has been much work done already in this area.

Within the Maryland Department of Health there is the Office for Genetics and People with Special Health Care Needs. The Office of Genetics and People with Special Health Care Needs has a Sickle Disease Follow-Up Program. This program follows

newborns, children, and young adults up to age 18, providing them and their families information about Sickle Cell Disease and other hemoglobin disorders, what to expect from your provider and specialist, guides to living with Sickle Cell disease, and other information pertaining to daycare, school, sports, transitioning to an adult provider, web resources and organizations of interest to persons with Sickle Cell disease. The work in this area is quite comprehensive. Additionally, the Office of Genetics and People with Special Health Care Needs staffs the Statewide Steering Committee on Services for Adults with Sickle Cell Disease. This Committee was first established in October 2007 under Chapter 435, Acts of 2007.

The Committee is charged with educating those with sickle cell disease, health care providers, and the public about State care and treatment. For that purpose, the Committee establishes partnerships with institutions and communities, as well as a statewide network of service providers for adults with sickle cell disease. Moreover, to implement or support its recommendations for action studies, policy, regulations, or laws, the Committee identifies funding sources, both private and from State, federal or local governments.

In consultation with the Committee, the Maryland Department of Health may provide some services relating to sickle cell disease. These services include educational programs; social services support; testing; genetic counseling; assistance with reimbursement for medical expenses; education and counseling services for parents of newborns with the sickle cell trait; and any other services that decrease the use of acute care services by persons with sickle cell disease (Chapter 452, Acts of 2019).

From May 2009 to July 2019, the Committee did not meet. However, it was reactivated by legislation in 2019 (Chapter 452, Acts of 2019). The Committee is comprised of medical clinicians and experts, advocates, individuals with sickle cell disease, educators, community representatives appointed by the Health Secretary. The Steering Committee is charged with establishing institution and community partnerships; a statewide network of stakeholders who care for individuals with sickle cell disease; educating individuals with sickle cell disease, the public, and health care providers about the State options for care of sickle cell disease; and identifying funding sources for implementing or supporting the actions, studies, policies, regulations, or laws recommended by the Steering Committee, including funding from: (i) state, federal, and local government sources; and (ii) private sources.

The Statewide Steering Committee on Services for Adults with Sickle Cell Disease may be the most effective primary convener on studies of Sickle Cell Disease. The MHCC lacks the subject specific expertise on this condition, but MHCC could support the Committee in the conduct of the studies. Our streamlined process for awarding contracts and grants may be especially useful given the short turnaround for work envisioned under HB 1192. Although the General Assembly is considering many new assignments for the MHCC,



we could play a supportive role to the Statewide Steering Committee on Services for Adults with Sickle Cell Disease in the completion of the studies.

If you would like to discuss this further or have any questions, please contact Tracey DeShields, Director, Policy Development and External Affairs at tracey.deshields2@maryland.gov.

Sincerely,



Andrew Pollack
Chair, MHCC



Ben Steffen
Executive Director, MHCC

cc: The Honorable Edith J. Patterson, Delegate
Tracey DeShields, Director, Policy Development and External Affairs, MHCC

