A BILL ENTITLED

AN ACT concerning

Public Health – Sickle Cell Disease Registry – Establishment

FOR the purpose of requiring the Maryland Department of Health to establish and maintain a registry of individuals diagnosed with sickle cell disease for a certain purpose; requiring the Department to periodically publish information identifying areas with statistically high populations of individuals with sickle cell disease; and generally relating to a sickle cell disease registry.

BY adding to

Article – Health – General
Section 18–508
Annotated Code of Maryland
(2019 Replacement Volume and 2021 Supplement)

SEC 1. BE IT ENACTED BY THE GENERAL ASSEMBLY OF MARYLAND, That the Laws of Maryland read as follows:

Article – Health – General

18–508.

(A) THE DEPARTMENT SHALL ESTABLISH AND MAINTAIN A REGISTRY OF INDIVIDUALS DIAGNOSED WITH SICKLE CELL DISEASE FOR USE AS A SINGLE REPOSITORY OF ACCURATE, COMPLETE RECORDS TO AID IN PROMOTING THE SITING OF THE FOLLOWING HEALTH CARE PROVIDERS IN AREAS WITH STATISTICALLY HIGH POPULATIONS OF INDIVIDUALS WITH SICKLE CELL DISEASE:

(1) HEALTH CARE FACILITIES THAT PROVIDE INFUSION THERAPY;
AND

EXPLANATION: CAPITALS INDICATE MATTER ADDED TO EXISTING LAW.
[Brackets] indicate matter deleted from existing law.
(2) **Hematologist Offices.**

(B) **The sickle cell disease registry established under subsection (a) of this section shall include:**

(1) A record of individuals in the State who have been diagnosed with sickle cell disease; and

(2) Any other information regarding individuals who have been diagnosed with sickle cell disease that the Department considers necessary and appropriate for inclusion on the registry.

(C) (1) The Department shall establish a process and guidelines for:

   (i) Obtaining information regarding an individual diagnosed with sickle cell disease from health care facilities for use in the registry; and

   (ii) Ensuring that the registry and the process of obtaining information for the registry comply with the requirements of § 18–504 of this subtitle, § 13–109 of this article, the Health Insurance Portability and Accountability Act of 1996, and any other applicable privacy law.

(2) The Department may use any available sources of data for the registry or as part of the process and guidelines established under paragraph (1) of this subsection, including:

   (i) Data from the designated Health Information Exchange in the State;

   (ii) Census–tract level data; and

   (iii) Information collected from vital records.

(D) A health care provider who provides health care to an individual with sickle cell disease shall provide to the Department any information in the form and manner required by the guidelines established under subsection (c) of this section.

(E) To the extent authorized by law, the Department shall periodically publish information identifying areas with statistically
HIGH POPULATIONS OF INDIVIDUALS WITH SICKLE CELL DISEASE, WHICH MAY INCLUDE INFORMATION PUBLISHED IN A MAP.

SECTION 2. AND BE IT FURTHER ENACTED, That this Act shall take effect October 1, 2022.