SENATE BILL 859

By: Senator Watson
Introduced and read first time: February 7, 2022
Assigned to: Finance

Committee Report: Favorable with amendments
Senate action: Adopted
Read second time: March 7, 2022

CHAPTER _____

1 AN ACT concerning

2 Public Health – Sickle Cell Disease Registry – Establishment

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

8 BY adding to
9 Article – Health – General
10 Section 18–508
11 Annotated Code of Maryland
12 (2019 Replacement Volume and 2021 Supplement)

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

15 Article – Health – General

16 18–508.

17 (A) THE DEPARTMENT SHALL ESTABLISH AND MAINTAIN A REGISTRY OF
18 INDIVIDUALS DIAGNOSED WITH SICKLE CELL DISEASE FOR USE AS A SINGLE
19 REPOSITORY OF ACCURATE, COMPLETE RECORDS TO AID IN PROMOTING THE SITING

EXPLANATION: CAPITALS INDICATE MATTER ADDED TO EXISTING LAW.
[Brackets] indicate matter deleted from existing law.
Underlining indicates amendments to bill.
Strike out indicates matter stricken from the bill by amendment or deleted from the law by amendment.
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

(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; AND

(III) INTEGRATING THE REGISTRY WITH THE
STATE–DESIGNATED HEALTH INFORMATION EXCHANGE.

(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.

Approved:

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Governor.

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President of the Senate.

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Speaker of the House of Delegates.