## **SENATE BILL 859**

J1 2lr2941 CF HB 1176

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

## 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.
- 8 BY adding to

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- 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.

<u>Underlining</u> indicates amendments to bill.

Strike out indicates matter stricken from the bill by amendment or deleted from the law by amendment.



- $^2$ 1 OF THE FOLLOWING HEALTH CARE PROVIDERS IN AREAS WITH STATISTICALLY HIGH 2 POPULATIONS OF INDIVIDUALS WITH SICKLE CELL DISEASE: 3 **(1)** HEALTH CARE FACILITIES THAT PROVIDE INFUSION THERAPY; 4 AND 5 **(2)** HEMATOLOGIST OFFICES. 6 (B) THE SICKLE CELL DISEASE REGISTRY ESTABLISHED UNDER 7 SUBSECTION (A) OF THIS SECTION SHALL INCLUDE: 8 A RECORD OF INDIVIDUALS IN THE STATE WHO HAVE BEEN 9 DIAGNOSED WITH SICKLE CELL DISEASE; AND 10 ANY OTHER INFORMATION REGARDING INDIVIDUALS WHO HAVE BEEN DIAGNOSED WITH SICKLE CELL DISEASE THAT THE DEPARTMENT CONSIDERS 11 12 NECESSARY AND APPROPRIATE FOR INCLUSION ON THE REGISTRY. 13 (C) THE DEPARTMENT SHALL ESTABLISH A PROCESS AND **(1)** 14 **GUIDELINES FOR:** 15 (I)OBTAINING INFORMATION REGARDING AN INDIVIDUAL 16 DIAGNOSED WITH SICKLE CELL DISEASE FROM HEALTH CARE FACILITIES FOR USE 17 IN THE REGISTRY; AND 18 ENSURING THAT THE REGISTRY AND THE PROCESS OF (II)OBTAINING INFORMATION FOR THE REGISTRY COMPLY WITH THE REQUIREMENTS 19 OF § 18-504 OF THIS SUBTITLE, § 13-109 OF THIS ARTICLE, THE HEALTH 20 21INSURANCE PORTABILITY AND ACCOUNTABILITY ACT OF 1996, AND ANY OTHER 22APPLICABLE PRIVACY LAW; AND 23 (III) INTEGRATING WITH THE REGISTRY THE STATE-DESIGNATED HEALTH INFORMATION EXCHANGE. 24
- 25**(2)** THE DEPARTMENT MAY USE ANY AVAILABLE SOURCES OF DATA FOR THE REGISTRY OR AS PART OF THE PROCESS AND GUIDELINES ESTABLISHED 26 UNDER PARAGRAPH (1) OF THIS SUBSECTION, INCLUDING: 27
- DATA FROM THE DESIGNATED HEALTH INFORMATION 28**(I)** 29EXCHANGE IN THE STATE;
- 30 (II)CENSUS-TRACT LEVEL DATA; AND
- 31 (III) INFORMATION COLLECTED FROM VITAL RECORDS.

1 2 3 4	(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.
5 6 7 8	(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.
9 10	SECTION 2. AND BE IT FURTHER ENACTED, That this Act shall take effect October 1, 2022.
	Approved:
	Governor.
	President of the Senate.

Speaker of the House of Delegates.