

HOUSE BILL 1176

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2lr2494
CF SB 859

By: **Delegate McComas**

Introduced and read first time: February 11, 2022

Assigned to: Health and Government Operations

A BILL ENTITLED

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**
20 **OF THE FOLLOWING HEALTH CARE PROVIDERS IN AREAS WITH STATISTICALLY HIGH**
21 **POPULATIONS OF INDIVIDUALS WITH SICKLE CELL DISEASE:**

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

EXPLANATION: CAPITALS INDICATE MATTER ADDED TO EXISTING LAW.

[Brackets] indicate matter deleted from existing law.



1 **(2) HEMATOLOGIST OFFICES.**

2 **(B) THE SICKLE CELL DISEASE REGISTRY ESTABLISHED UNDER**
3 **SUBSECTION (A) OF THIS SECTION SHALL INCLUDE:**

4 **(1) A RECORD OF INDIVIDUALS IN THE STATE WHO HAVE BEEN**
5 **DIAGNOSED WITH SICKLE CELL DISEASE; AND**

6 **(2) ANY OTHER INFORMATION REGARDING INDIVIDUALS WHO HAVE**
7 **BEEN DIAGNOSED WITH SICKLE CELL DISEASE THAT THE DEPARTMENT CONSIDERS**
8 **NECESSARY AND APPROPRIATE FOR INCLUSION ON THE REGISTRY.**

9 **(C) (1) THE DEPARTMENT SHALL ESTABLISH A PROCESS AND**
10 **GUIDELINES FOR:**

11 **(I) OBTAINING INFORMATION REGARDING AN INDIVIDUAL**
12 **DIAGNOSED WITH SICKLE CELL DISEASE FROM HEALTH CARE FACILITIES FOR USE**
13 **IN THE REGISTRY; AND**

14 **(II) ENSURING THAT THE REGISTRY AND THE PROCESS OF**
15 **OBTAINING INFORMATION FOR THE REGISTRY COMPLY WITH THE REQUIREMENTS**
16 **OF § 18-504 OF THIS SUBTITLE, § 13-109 OF THIS ARTICLE, THE HEALTH**
17 **INSURANCE PORTABILITY AND ACCOUNTABILITY ACT OF 1996, AND ANY OTHER**
18 **APPLICABLE PRIVACY LAW.**

19 **(2) THE DEPARTMENT MAY USE ANY AVAILABLE SOURCES OF DATA**
20 **FOR THE REGISTRY OR AS PART OF THE PROCESS AND GUIDELINES ESTABLISHED**
21 **UNDER PARAGRAPH (1) OF THIS SUBSECTION, INCLUDING:**

22 **(I) DATA FROM THE DESIGNATED HEALTH INFORMATION**
23 **EXCHANGE IN THE STATE;**

24 **(II) CENSUS-TRACT LEVEL DATA; AND**

25 **(III) INFORMATION COLLECTED FROM VITAL RECORDS.**

26 **(D) A HEALTH CARE PROVIDER WHO PROVIDES HEALTH CARE TO AN**
27 **INDIVIDUAL WITH SICKLE CELL DISEASE SHALL PROVIDE TO THE DEPARTMENT ANY**
28 **INFORMATION IN THE FORM AND MANNER REQUIRED BY THE GUIDELINES**
29 **ESTABLISHED UNDER SUBSECTION (C) OF THIS SECTION.**

30 **(E) TO THE EXTENT AUTHORIZED BY LAW, THE DEPARTMENT SHALL**
31 **PERIODICALLY PUBLISH INFORMATION IDENTIFYING AREAS WITH STATISTICALLY**

1 HIGH POPULATIONS OF INDIVIDUALS WITH SICKLE CELL DISEASE, WHICH MAY
2 INCLUDE INFORMATION PUBLISHED IN A MAP.

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