

SENATE BILL 584

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3lr2191
CF HB 703

By: **Senators Gile and Elfreth**

Introduced and read first time: February 6, 2023

Assigned to: Finance

A BILL ENTITLED

1 AN ACT concerning

2 **Public Health – Parkinson’s Disease Registry – Established**

3 FOR the purpose of establishing a Parkinson’s Disease Registry in the Maryland
4 Department of Health; requiring the Department to collect certain data for the
5 Registry; authorizing the Department to share certain information in the Registry
6 with certain entities under certain conditions; providing for the confidentiality of
7 information collected under this Act; requiring the Department to maintain a record
8 of individuals granted access to confidential information in the Registry; and
9 generally relating to the establishment of a Parkinson’s Disease Registry.

10 BY repealing and reenacting, with amendments,

11 Article – Health – General

12 Section 18–1201 and 18–1203

13 Annotated Code of Maryland

14 (2019 Replacement Volume and 2022 Supplement)

15 BY repealing

16 Article – Health – General

17 Section 18–1202

18 Annotated Code of Maryland

19 (2019 Replacement Volume and 2022 Supplement)

20 BY adding to

21 Article – Health – General

22 Section 18–1202 and 18–1204 through 18–1210

23 Annotated Code of Maryland

24 (2019 Replacement Volume and 2022 Supplement)

25 SECTION 1. BE IT ENACTED BY THE GENERAL ASSEMBLY OF MARYLAND,

26 That the Laws of Maryland read as follows:

EXPLANATION: CAPITALS INDICATE MATTER ADDED TO EXISTING LAW.

[Brackets] indicate matter deleted from existing law.



Article – Health – General

2 18-1201.

3 (a) In this subtitle the following words have the meanings indicated.

4 (b) "Advisory Committee" means the Parkinson's Disease Registry Advisory
5 Committee.

6 (c) (1) "PARKINSONISMS" MEANS CONDITIONS RELATED TO
7 PARKINSON'S DISEASE THAT CAUSE A COMBINATION OF THE MOVEMENT
8 ABNORMALITIES SEEN IN PARKINSON'S DISEASE.

12 **(D)** “Parkinson’s disease” means a chronic and progressive disorder resulting from
13 deficiency of the neurotransmitter dopamine as the consequence of specific degenerative
14 changes in the area of the brain called the basal ganglia, characterized by tremors at rest,
15 slow movements, muscle rigidity, stooped posture, and unsteady or shuffling gait.

16 (E) "REGISTRY" MEANS THE PARKINSON'S DISEASE REGISTRY.

17 [18-1202.

18 There is a Parkinson's Disease Registry Advisory Committee in the Department.]

19 18-1202.

20 THERE IS A PARKINSON'S DISEASE REGISTRY IN THE DEPARTMENT.

21 18-1203.

22 (A) THERE IS A PARKINSON'S DISEASE REGISTRY ADVISORY COMMITTEE
23 IN THE DEPARTMENT.

24 [(a)] (B) The Advisory Committee shall:

25 (1) Assist in the development and implementation of a Parkinson's Disease
26 Registry;

(3) Advise the Department on Parkinson's disease and maintaining a Parkinson's Disease Registry.

3 [(b)] (c) (1) The Secretary shall appoint individuals to serve on the Advisory
4 Committee, including:

5 (i) A neurologist;

6 (ii) A movement disorder specialist;

7 (iii) A primary care provider;

8 (iv) A physician informaticist;

9 (v) A patient with Parkinson's disease;

10 (vi) A public health professional;

(vii) A population health researcher familiar with disease registries;

12 (viii) A Parkinson's disease researcher; and

13 (ix) Any other individuals the Secretary determines are necessary.

14 (2) The Secretary shall establish:

15 (i) The duration of term limits for members of the Advisory
16 Committee;

17 (ii) The frequency of meetings of the Advisory Committee;

18 (iii) Rules and procedures for conducting business of the Advisory
19 Committee; and

20 (iv) Any other rules necessary for the Advisory Committee to
21 function effectively.

22 18-1204.

23 (A) THE DEPARTMENT SHALL COLLECT DATA FOR THE REGISTRY,
24 INCLUDING DATA ON THE INCIDENCE OF PARKINSON'S DISEASE IN THE STATE AND
25 RELATED EPIDEMIOLOGICAL DATA.

26 (B) THE ADVISORY COMMITTEE, IN CONSULTATION WITH THE
27 DEPARTMENT SHALL:

3 (I) PATIENT DEMOGRAPHICS, INCLUDING GEOGRAPHY; AND

4 (II) DIAGNOSES; AND

5 (2) PERIODICALLY REVIEW THE DATA COLLECTED FOR THE
6 REGISTRY TO ASSESS WHETHER THE:

7 (I) DATA INCLUDES SUFFICIENT INFORMATION TO ENSURE
8 THERE ARE NO DUPLICATED PATIENT RECORDS IN THE REGISTRY; AND

9 (II) CATEGORIES OF DATA COLLECTED SHOULD BE ALTERED.

10 18-1205.

11 (A) (1) UNLESS OTHERWISE PROVIDED IN THIS SUBTITLE, ALL
12 INFORMATION COLLECTED FOR THE REGISTRY UNDER THIS SUBTITLE SHALL BE
13 CONFIDENTIAL.

17 (B) THE DEPARTMENT, IN CONSULTATION WITH THE ADVISORY
18 COMMITTEE, SHALL ESTABLISH A SYSTEM FOR THE COLLECTION OF DATA FOR THE
19 REGISTRY AND DISSEMINATION OF INFORMATION DETERMINING THE INCIDENCE
20 AND PREVALENCE OF PARKINSON'S DISEASE AND RELATED PARKINSONISMS.

21 (c) (1) THE DEPARTMENT, IN CONSULTATION WITH THE ADVISORY
22 COMMITTEE, SHALL:

28 (II) PROVIDE AN OPPORTUNITY TO OPT OUT OF PARTICIPATION
29 IN THE REGISTRY.

6 1. SHALL RECORD AN INCIDENCE OF A PATIENT WITH
7 PARKINSON'S DISEASE; AND

10 (D) THE DEPARTMENT MAY:

20 (E) AT LEAST 180 DAYS BEFORE THE DEPARTMENT ADOPTS MANDATORY
21 REPORTING OF PARKINSON'S DISEASE AND RELATED PARKINSONISMS, THE
22 DEPARTMENT SHALL PROVIDE NOTIFICATION OF THE MANDATORY REPORTING OF
23 PARKINSON'S DISEASE AND RELATED PARKINSONISMS:

24 (1) ON THE DEPARTMENT'S WEBSITE;

25 (2) DIRECTLY TO ASSOCIATIONS REPRESENTING HOSPITALS,
26 HEALTH CARE PROFESSIONALS, AND OTHER HEALTH CARE PROVIDERS IN THE
27 STATE; AND

30 (F) (1) A NURSE PRACTITIONER, PHYSICIAN, OR PHYSICIAN ASSISTANT
31 WHO DIAGNOSES PATIENTS WITH PARKINSON'S DISEASE AND RELATED
32 PARKINSONISMS SHALL REPORT EACH CASE OF PARKINSON'S DISEASE AND

1 RELATED PARKINSONISMS TO THE REGISTRY IN A FORMAT DETERMINED BY THE
2 DEPARTMENT.

3 (2) THE DEPARTMENT MAY USE EXISTING REPORTING PROCEDURES
4 TO IMPLEMENT THE REQUIREMENT UNDER PARAGRAPH (1) OF THIS SUBSECTION
5 FOR DIAGNOSIS REPORTING AND DATA SUBMISSION BY A NURSE PRACTITIONER,
6 PHYSICIAN, OR PHYSICIAN ASSISTANT.

7 18-1206.

8 (A) THE DEPARTMENT MAY ENTER INTO AGREEMENTS TO PROVIDE DATA
9 COLLECTED IN THE REGISTRY WITH PARKINSON'S DISEASE REGISTRIES IN OTHER
10 STATES, FEDERAL PARKINSON'S DISEASE CONTROL AGENCIES, LOCAL HEALTH
11 DEPARTMENTS, OR HEALTH RESEARCHERS FOR THE STUDY OF PARKINSON'S
12 DISEASE AND RELATED PARKINSONISMS.

13 (B) (1) BEFORE CONFIDENTIAL INFORMATION IS DISCLOSED UNDER
14 SUBSECTION (A) OF THIS SECTION, THE DEPARTMENT SHALL RECEIVE A WRITTEN
15 AGREEMENT FROM THE PARTNERING ENTITY TO MAINTAIN THE CONFIDENTIALITY
16 OF THE INFORMATION.

17 (2) IF THE ENTITY RECEIVING CONFIDENTIAL DATA FROM THE
18 REGISTRY IS A RESEARCH ENTITY, THE RESEARCH ENTITY SHALL:

19 (I) OBTAIN APPROVAL FROM THE COMMITTEE AT THE
20 RESEARCH ENTITY THAT NORMALLY REVIEWS RESEARCH PROJECTS FOR THE
21 PROTECTION OF HUMAN SUBJECTS ESTABLISHED IN ACCORDANCE WITH TITLE 45
22 OF THE CODE OF FEDERAL REGULATIONS; AND

23 (II) PROVIDE DOCUMENTATION TO THE DEPARTMENT THAT
24 DEMONSTRATES, TO THE DEPARTMENT'S SATISFACTION, THAT THE RESEARCH
25 ENTITY HAS ESTABLISHED PROCEDURES AND THE ABILITY TO MAINTAIN THE
26 CONFIDENTIALITY OF THE DISCLOSED INFORMATION.

27 (C) THE DEPARTMENT SHALL ESTABLISH PROCEDURES TO REVIEW AND
28 APPROVE REQUESTS TO USE REGISTRY DATA FOR SCIENTIFIC RESEARCH.

29 18-1207.

30 (A) NOTWITHSTANDING ANY OTHER PROVISION OF LAW OR RULE OF
31 PROCEDURE OR EVIDENCE IN THE MARYLAND RULES:

32 (1) A DATA DISCLOSURE AUTHORIZED BY THIS SUBTITLE MAY NOT:

3 (II) BE USED FOR A PURPOSE OTHER THAN THE PURPOSE FOR
4 THE DISCLOSURE; OR

5 (III) BE FURTHER DISCLOSED;

6 (2) THE CONFIDENTIAL INFORMATION COLLECTED FOR THE
7 REGISTRY MAY NOT BE MADE AVAILABLE FOR SUBPOENA, DISCLOSED,
8 DISCOVERABLE, OR COMPELLED TO BE PRODUCED IN ANY CIVIL, CRIMINAL,
9 ADMINISTRATIVE, OR OTHER PROCEEDING; AND

10 (3) THE CONFIDENTIAL INFORMATION COLLECTED FOR THE
11 REGISTRY MAY NOT BE DEEMED ADMISSIBLE AS EVIDENCE IN ANY CIVIL, CRIMINAL,
12 ADMINISTRATIVE, TRIBUNAL, OR OTHER PROCEEDING.

13 (B) (1) THIS SECTION DOES NOT PREEMPT THE AUTHORITY OF A HEALTH
14 CARE PROVIDER, AS DEFINED IN § 19-132 OF THIS ARTICLE, PROVIDING
15 DIAGNOSTIC SERVICES OR TREATMENT TO PATIENTS WITH PARKINSON'S DISEASE
16 OR RELATED PARKINSONISMS TO MAINTAIN A PARKINSON'S DISEASE REGISTRY.

21 18-1208.

22 (A) THE DEPARTMENT SHALL MAINTAIN A RECORD OF INDIVIDUALS
23 GRANTED ACCESS TO CONFIDENTIAL INFORMATION FROM THE REGISTRY.

24 **(B) THE DEPARTMENT MAY NOT DENY A REQUEST FOR INSPECTION OF THE**
25 **RECORD MAINTAINED UNDER SUBSECTION (A) OF THIS SECTION UNDER TITLE 4 OF**
26 **THE GENERAL PROVISIONS ARTICLE.**

27 (c) THE RECORD MAINTAINED UNDER SUBSECTION (A) OF THIS SECTION
28 SHALL INCLUDE THE ACCESSING INDIVIDUAL'S:

29 (1) NAME:

30 (2) TITLE:

- (3) ADDRESS;**
- (4) ORGANIZATIONAL AFFILIATION;**
- (5) DATES OF ACCESS; AND**
- (6) PURPOSE FOR ACCESSING THE INFORMATION.**

5 18-1209.

6 THE DEPARTMENT SHALL ADOPT REGULATIONS NECESSARY TO CARRY OUT
7 THIS SUBTITLE.

8 18-1210.

15 (B) THE DEPARTMENT SHALL POST THE REPORT REQUIRED UNDER
16 SUBSECTION (A) OF THIS SECTION ON A DEDICATED WEBSITE ACCESSIBLE TO THE
17 PUBLIC.

18 SECTION 2. AND BE IT FURTHER ENACTED, That this Act shall take effect
19 October 1, 2023.