

SENATE BILL 740

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2lr1933
CF HB 1412

By: **Senators Elfreth, Beidle, Feldman, and Klausmeier**

Introduced and read first time: February 7, 2022

Assigned to: Finance

Committee Report: Favorable with amendments

Senate action: Adopted

Read second time: March 24, 2022

CHAPTER _____

1 AN ACT concerning

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

3 FOR the purpose of ~~establishing a Parkinson’s Disease Registry in the Maryland~~
4 ~~Department of Health~~; requiring the Maryland Department of Health to establish a
5 Parkinson’s Disease Registry Advisory Committee; ~~authorizing the Department to~~
6 ~~share certain information in the Registry with certain entities under certain~~
7 ~~conditions; providing for the confidentiality of information collected under this Act;~~
8 and generally relating to the establishment of a Parkinson’s ~~disease registry~~ Disease
9 Registry Advisory Committee.

10 BY adding to

11 Article – Health – General

12 Section 18–1201 through ~~18–1207~~ 18–1203 to be under the new subtitle “Subtitle 12.

13 Parkinson’s Disease”

14 Annotated Code of Maryland

15 (2019 Replacement Volume and 2021 Supplement)

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

17 That the Laws of Maryland read as follows:

18 **Article – Health – General**

19 **SUBTITLE 12. PARKINSON’S DISEASE.**

20 **18–1201.**

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.



1 (A) IN THIS SUBTITLE THE FOLLOWING WORDS HAVE THE MEANINGS
2 INDICATED.

3 (B) "ADVISORY COMMITTEE" MEANS THE PARKINSON'S DISEASE
4 REGISTRY ADVISORY COMMITTEE.

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

8 ~~(2) "PARKINSONISMS" INCLUDES MULTIPLE SYSTEM ATROPHY,
9 DEMENTIA WITH LEWY BODIES, CORTICOBASAL DEGENERATION, AND
10 PROGRESSIVE SUPRANUCLEAR PALSY.~~

11 ~~(D)~~ (C) "PARKINSON'S DISEASE" MEANS A CHRONIC AND PROGRESSIVE
12 DISORDER RESULTING FROM DEFICIENCY OF THE NEUROTRANSMITTER DOPAMINE
13 AS THE CONSEQUENCE OF SPECIFIC DEGENERATIVE CHANGES IN THE AREA OF THE
14 BRAIN CALLED THE BASAL GANGLIA, CHARACTERIZED BY TREMORS AT REST, SLOW
15 MOVEMENTS, MUSCLE RIGIDITY, STOOPED POSTURE, AND UNSTEADY OR
16 SHUFFLING GAIT.

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

18 18-1202.

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

21 18-1203.

22 (A) THE ~~DEPARTMENT~~ ADVISORY COMMITTEE SHALL ~~ESTABLISH A~~
23 ~~PARKINSON'S DISEASE REGISTRY ADVISORY COMMITTEE TO:~~

24 (1) ASSIST IN THE DEVELOPMENT AND IMPLEMENTATION OF ~~THE A~~ A
25 PARKINSON'S DISEASE REGISTRY;

26 (2) DETERMINE WHAT DATA SHALL BE COLLECTED AND BE STORED
27 IN THE A PARKINSON'S DISEASE REGISTRY AND THE METHODS TO ENSURE THE
28 PRIVACY AND CONFIDENTIALITY OF DATA COLLECTED AND STORED IN THE
29 REGISTRY; AND

30 (3) ADVISE THE DEPARTMENT ON PARKINSON'S DISEASE AND
31 MAINTAINING ~~THE A~~ PARKINSON'S DISEASE REGISTRY.

1 **(B) (1) THE SECRETARY SHALL APPOINT INDIVIDUALS TO SERVE ON THE**
2 **ADVISORY COMMITTEE, INCLUDING:**

3 **(I) A NEUROLOGIST;**

4 **(II) A MOVEMENT DISORDER SPECIALIST;**

5 **(III) A PRIMARY CARE PROVIDER;**

6 **(IV) A PHYSICIAN INFORMATICIST;**

7 **(V) A PATIENT WITH PARKINSON'S DISEASE;**

8 **(VI) A PUBLIC HEALTH PROFESSIONAL;**

9 **(VII) A POPULATION HEALTH RESEARCHER FAMILIAR WITH**
10 **DISEASE REGISTRIES;**

11 **(VIII) A PARKINSON'S DISEASE RESEARCHER; AND**

12 **(IX) ANY OTHER INDIVIDUALS THE SECRETARY DETERMINES**
13 **ARE NECESSARY.**

14 **(2) THE SECRETARY SHALL ESTABLISH:**

15 **(I) THE DURATION OF TERM LIMITS FOR MEMBERS OF THE**
16 **ADVISORY COMMITTEE;**

17 **(II) THE FREQUENCY OF MEETINGS OF THE ADVISORY**
18 **COMMITTEE;**

19 **(III) RULES AND PROCEDURES FOR CONDUCTING BUSINESS OF**
20 **THE ADVISORY COMMITTEE; AND**

21 **(IV) ANY OTHER RULES NECESSARY FOR THE ADVISORY**
22 **COMMITTEE TO FUNCTION EFFECTIVELY.**

23 ~~18-1204.~~

24 ~~**(A) (1) UNLESS OTHERWISE PROVIDED IN THIS SUBTITLE, ALL**~~
25 ~~**INFORMATION COLLECTED FOR THE REGISTRY UNDER THIS SUBTITLE SHALL BE**~~
26 ~~**CONFIDENTIAL.**~~

1 ~~(2) THE DEPARTMENT SHALL IMPLEMENT A CODING SYSTEM THAT~~
2 ~~REMOVES ANY PERSONALLY IDENTIFIABLE INFORMATION OF AN INDIVIDUAL FROM~~
3 ~~COLLECTED DATA.~~

4 ~~(B) THE DEPARTMENT, IN CONSULTATION WITH THE ADVISORY~~
5 ~~COMMITTEE, SHALL ESTABLISH A SYSTEM FOR THE COLLECTION AND~~
6 ~~DISSEMINATION OF INFORMATION DETERMINING THE INCIDENCE AND~~
7 ~~PREVALENCE OF PARKINSON'S DISEASE AND RELATED PARKINSONISMS.~~

8 ~~(C) (1) THE DEPARTMENT, IN CONSULTATION WITH THE ADVISORY~~
9 ~~COMMITTEE, SHALL:~~

10 ~~(I) NOTIFY, IN WRITING AND ORALLY, ALL INDIVIDUALS IN THE~~
11 ~~STATE DIAGNOSED WITH PARKINSON'S DISEASE OR RELATED PARKINSONISMS~~
12 ~~ABOUT THE CREATION OF THE REGISTRY, DATA COLLECTION ASSOCIATED WITH~~
13 ~~THE REGISTRY, AND THE RIGHT TO OPT OUT OF PARTICIPATION IN THE REGISTRY;~~
14 ~~AND~~

15 ~~(II) PROVIDE AN OPPORTUNITY TO OPT OUT OF PARTICIPATION~~
16 ~~IN THE REGISTRY.~~

17 ~~(2) (I) AN INDIVIDUAL WITH PARKINSON'S DISEASE MAY OPT OUT~~
18 ~~OF PARTICIPATING IN THE REGISTRY.~~

19 ~~(II) IF AN INDIVIDUAL OPTS OUT OF PARTICIPATION IN THE~~
20 ~~REGISTRY, THE DEPARTMENT:~~

21 ~~1. SHALL RECORD AN INCIDENCE OF A PATIENT WITH~~
22 ~~PARKINSON'S DISEASE; AND~~

23 ~~2. MAY NOT RECORD ANY ADDITIONAL INFORMATION~~
24 ~~ABOUT THE INDIVIDUAL WHO OPTED OUT.~~

25 ~~(D) THE DEPARTMENT MAY:~~

26 ~~(1) CREATE, REVIEW, AND REVISE A LIST OF DATA POINTS REQUIRED~~
27 ~~AS PART OF MANDATED PARKINSON'S DISEASE REPORTING UNDER THIS SECTION,~~
28 ~~INCLUDING NECESSARY TRIGGERING DIAGNOSTIC CONDITIONS THAT ARE~~
29 ~~CONSISTENT WITH THE LATEST INTERNATIONAL STATISTICAL CLASSIFICATION OF~~
30 ~~DISEASES AND RELATED HEALTH PROBLEMS; AND~~

31 ~~(2) IMPLEMENT THE COLLECTION OF DATA POINTS ON THE LIST~~
32 ~~CREATED UNDER ITEM (1) OF THIS SUBSECTION THROUGH A BULLETIN, OR SIMILAR~~

1 ~~INSTRUCTION, TO NURSE PRACTITIONERS, PHYSICIANS, AND PHYSICIAN~~
2 ~~ASSISTANTS.~~

3 ~~(E) AT LEAST 180 DAYS DAY BEFORE THE DEPARTMENT ADOPTS~~
4 ~~MANDATORY REPORTING OF PARKINSON'S DISEASE AND RELATED PARKINSONISMS,~~
5 ~~THE DEPARTMENT SHALL PROVIDE NOTIFICATION OF THE MANDATORY REPORTING~~
6 ~~OF PARKINSON'S DISEASE AND RELATED PARKINSONISMS:~~

7 ~~(1) ON ITS WEBSITE;~~

8 ~~(2) DIRECTLY TO ASSOCIATIONS REPRESENTING HOSPITALS,~~
9 ~~HEALTH CARE PROFESSIONALS, AND OTHER HEALTH CARE PROVIDERS IN THE~~
10 ~~STATE; AND~~

11 ~~(3) DIRECTLY TO THE STATE BOARD OF NURSING AND THE STATE~~
12 ~~BOARD OF PHYSICIANS.~~

13 ~~(F) A NURSE PRACTITIONER, PHYSICIAN, OR PHYSICIAN ASSISTANT WHO~~
14 ~~DIAGNOSES PATIENTS WITH PARKINSON'S DISEASE AND RELATED PARKINSONISMS~~
15 ~~SHALL REPORT EACH CASE OF PARKINSON'S DISEASE AND RELATED~~
16 ~~PARKINSONISMS TO THE REGISTRY IN A FORMAT DETERMINED BY THE~~
17 ~~DEPARTMENT.~~

18 ~~18-1205.~~

19 ~~(A) THE DEPARTMENT MAY ENTER INTO AGREEMENTS TO PROVIDE DATA~~
20 ~~COLLECTED IN THE REGISTRY WITH PARKINSON'S DISEASE REGISTRIES IN OTHER~~
21 ~~STATES, FEDERAL PARKINSON'S DISEASE CONTROL AGENCIES, LOCAL HEALTH~~
22 ~~DEPARTMENTS, OR HEALTH RESEARCHERS FOR THE STUDY OF PARKINSON'S~~
23 ~~DISEASE AND RELATED PARKINSONISMS.~~

24 ~~(B) (1) BEFORE ANY CONFIDENTIAL INFORMATION IS DISCLOSED UNDER~~
25 ~~SUBSECTION (A) OF THIS SECTION, THE DEPARTMENT SHALL RECEIVE A WRITTEN~~
26 ~~AGREEMENT FROM THE PARTNERING ENTITY TO MAINTAIN THE CONFIDENTIALITY~~
27 ~~OF THE INFORMATION.~~

28 ~~(2) IF THE ENTITY RECEIVING CONFIDENTIAL DATA FROM THE~~
29 ~~REGISTRY IS A RESEARCH ENTITY, THE RESEARCH ENTITY SHALL:~~

30 ~~(i) OBTAIN APPROVAL FROM THE COMMITTEE AT THE~~
31 ~~RESEARCH INSTITUTION THAT NORMALLY REVIEWS RESEARCH PROJECTS FOR THE~~
32 ~~PROTECTION OF HUMAN SUBJECTS ESTABLISHED IN ACCORDANCE WITH TITLE 45~~
33 ~~OF THE CODE OF FEDERAL REGULATIONS; AND~~

~~(H) PROVIDE DOCUMENTATION TO THE DEPARTMENT THAT DEMONSTRATES, TO THE DEPARTMENT'S SATISFACTION, THAT THE RESEARCH ENTITY HAS ESTABLISHED PROCEDURES AND THE ABILITY TO MAINTAIN THE CONFIDENTIALITY OF THE DISCLOSED INFORMATION.~~

~~18 1206.~~

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

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

~~(I) INCLUDE INFORMATION OTHER THAN THE INFORMATION NECESSARY FOR THE PURPOSE OF THE DISCLOSURE;~~

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

~~(III) BE FURTHER DISCLOSED;~~

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

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

~~(B) (1) THIS SECTION DOES NOT PREEMPT THE AUTHORITY OF HEALTH CARE PROVIDERS, AS DEFINED IN § 19-132 OF THIS ARTICLE, PROVIDING DIAGNOSTIC SERVICES OR TREATMENT TO PATIENTS WITH PARKINSON'S DISEASE OR RELATED PARKINSONISMS TO MAINTAIN THEIR OWN PARKINSON'S DISEASE REGISTRIES.~~

~~(2) THIS SECTION DOES NOT PROHIBIT THE PUBLICATION OF REPORTS AND STATISTICAL COMPILATIONS THAT DO NOT IDENTIFY INDIVIDUALS WITH PARKINSON'S DISEASE OR RELATED PARKINSONISMS OR INDIVIDUAL SOURCES OF INFORMATION.~~

~~18 1207.~~

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

1 SECTION 2. AND BE IT FURTHER ENACTED, That, on or before January 1, 2023,
2 the Maryland Department of Health shall report to the Senate Finance Committee and the
3 House Health and Government Operations Committee, in accordance with § 2-1257 of the
4 State Government Article, on recommendations, including legislative recommendations, for
5 the establishment of a Parkinson's Disease Registry.

6 SECTION ~~2~~ 3. AND BE IT FURTHER ENACTED, That this Act shall take effect
7 ~~October~~ July 1, 2022.

Approved:

Governor.

President of the Senate.

Speaker of the House of Delegates.