

SENATE BILL 740

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

Introduced and read first time: February 7, 2022

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

9 BY adding to

10 Article – Health – General

11 Section 18–1201 through 18–1207 to be under the new subtitle “Subtitle 12.
12 Parkinson’s Disease”

13 Annotated Code of Maryland

14 (2019 Replacement Volume and 2021 Supplement)

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

17 **Article – Health – General**

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

19 **18–1201.**

20 **(A) IN THIS SUBTITLE THE FOLLOWING WORDS HAVE THE MEANINGS**
21 **INDICATED.**

22 **(B) “ADVISORY COMMITTEE” MEANS THE PARKINSON’S DISEASE**
23 **REGISTRY ADVISORY COMMITTEE.**

EXPLANATION: CAPITALS INDICATE MATTER ADDED TO EXISTING LAW.

[Brackets] indicate matter deleted from existing law.



1 (C) (1) “PARKINSONISMS” MEANS CONDITIONS RELATED TO
2 PARKINSON’S DISEASE THAT CAUSE A COMBINATION OF THE MOVEMENT
3 ABNORMALITIES SEEN IN PARKINSON’S DISEASE.

4 (2) “PARKINSONISMS” INCLUDES MULTIPLE SYSTEM ATROPHY,
5 DEMENTIA WITH LEWY BODIES, CORTICOBASAL DEGENERATION, AND
6 PROGRESSIVE SUPRANUCLEAR PALSY.

7 (D) “PARKINSON’S DISEASE” MEANS A CHRONIC AND PROGRESSIVE
8 DISORDER RESULTING FROM DEFICIENCY OF THE NEUROTRANSMITTER DOPAMINE
9 AS THE CONSEQUENCE OF SPECIFIC DEGENERATIVE CHANGES IN THE AREA OF THE
10 BRAIN CALLED THE BASAL GANGLIA, CHARACTERIZED BY TREMORS AT REST, SLOW
11 MOVEMENTS, MUSCLE RIGIDITY, STOOPED POSTURE, AND UNSTEADY OR
12 SHUFFLING GAIT.

13 (E) “REGISTRY” MEANS THE PARKINSON’S DISEASE REGISTRY.

14 18-1202.

15 THERE IS A PARKINSON’S DISEASE REGISTRY IN THE DEPARTMENT.

16 18-1203.

17 (A) THE DEPARTMENT SHALL ESTABLISH A PARKINSON’S DISEASE
18 REGISTRY ADVISORY COMMITTEE TO:

19 (1) ASSIST IN THE DEVELOPMENT AND IMPLEMENTATION OF THE
20 REGISTRY;

21 (2) DETERMINE WHAT DATA SHALL BE COLLECTED AND BE STORED
22 IN THE REGISTRY; AND

23 (3) ADVISE THE DEPARTMENT ON PARKINSON’S DISEASE AND
24 MAINTAINING THE REGISTRY.

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

27 (I) A NEUROLOGIST;

28 (II) A MOVEMENT DISORDER SPECIALIST;

- 1 (III) A PRIMARY CARE PROVIDER;
- 2 (IV) A PHYSICIAN INFORMATICIST;
- 3 (V) A PATIENT WITH PARKINSON'S DISEASE
- 4 (VI) A PUBLIC HEALTH PROFESSIONAL;
- 5 (VII) A POPULATION HEALTH RESEARCHER FAMILIAR WITH
6 DISEASE REGISTRIES;
- 7 (VIII) A PARKINSON'S DISEASE RESEARCHER; AND
- 8 (IX) ANY OTHER INDIVIDUALS THE SECRETARY DETERMINES
9 ARE NECESSARY.

10 (2) THE SECRETARY SHALL ESTABLISH:

- 11 (I) THE DURATION OF TERM LIMITS FOR MEMBERS OF THE
12 ADVISORY COMMITTEE;
- 13 (II) THE FREQUENCY OF MEETINGS OF THE ADVISORY
14 COMMITTEE;
- 15 (III) RULES AND PROCEDURES FOR CONDUCTING BUSINESS OF
16 THE ADVISORY COMMITTEE; AND
- 17 (IV) ANY OTHER RULES NECESSARY FOR THE ADVISORY
18 COMMITTEE TO FUNCTION EFFECTIVELY.

19 18-1204.

20 (A) (1) UNLESS OTHERWISE PROVIDED IN THIS SUBTITLE, ALL
21 INFORMATION COLLECTED FOR THE REGISTRY UNDER THIS SUBTITLE SHALL BE
22 CONFIDENTIAL.

23 (2) THE DEPARTMENT SHALL IMPLEMENT A CODING SYSTEM THAT
24 REMOVES ANY PERSONALLY IDENTIFIABLE INFORMATION OF AN INDIVIDUAL FROM
25 COLLECTED DATA.

26 (B) THE DEPARTMENT, IN CONSULTATION WITH THE ADVISORY
27 COMMITTEE, SHALL ESTABLISH A SYSTEM FOR THE COLLECTION AND

1 DISSEMINATION OF INFORMATION DETERMINING THE INCIDENCE AND
2 PREVALENCE OF PARKINSON'S DISEASE AND RELATED PARKINSONISMS.

3 (C) (1) THE DEPARTMENT, IN CONSULTATION WITH THE ADVISORY
4 COMMITTEE, SHALL:

5 (I) NOTIFY, IN WRITING AND ORALLY, ALL INDIVIDUALS IN THE
6 STATE DIAGNOSED WITH PARKINSON'S DISEASE OR RELATED PARKINSONISMS
7 ABOUT THE CREATION OF THE REGISTRY, DATA COLLECTION ASSOCIATED WITH
8 THE REGISTRY, AND THE RIGHT TO OPT OUT OF PARTICIPATION IN THE REGISTRY;
9 AND

10 (II) PROVIDE AN OPPORTUNITY TO OPT OUT OF PARTICIPATION
11 IN THE REGISTRY.

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

14 (II) IF AN INDIVIDUAL OPTS OUT OF PARTICIPATION IN THE
15 REGISTRY, THE DEPARTMENT:

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

18 2. MAY NOT RECORD ANY ADDITIONAL INFORMATION
19 ABOUT THE INDIVIDUAL WHO OPTED OUT.

20 (D) THE DEPARTMENT MAY:

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

26 (2) IMPLEMENT THE COLLECTION OF DATA POINTS ON THE LIST
27 CREATED UNDER ITEM (1) OF THIS SUBSECTION THROUGH A BULLETIN, OR SIMILAR
28 INSTRUCTION, TO NURSE PRACTITIONERS, PHYSICIANS, AND PHYSICIAN
29 ASSISTANTS.

30 (E) AT LEAST 180 DAYS DAY BEFORE THE DEPARTMENT ADOPTS
31 MANDATORY REPORTING OF PARKINSON'S DISEASE AND RELATED PARKINSONISMS,

1 THE DEPARTMENT SHALL PROVIDE NOTIFICATION OF THE MANDATORY REPORTING
2 OF PARKINSON'S DISEASE AND RELATED PARKINSONISMS:

3 (1) ON ITS WEBSITE;

4 (2) DIRECTLY TO ASSOCIATIONS REPRESENTING HOSPITALS,
5 HEALTH CARE PROFESSIONALS, AND OTHER HEALTH CARE PROVIDERS IN THE
6 STATE; AND

7 (3) DIRECTLY TO THE STATE BOARD OF NURSING AND THE STATE
8 BOARD OF PHYSICIANS.

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

14 18-1205.

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

20 (B) (1) BEFORE ANY CONFIDENTIAL INFORMATION IS DISCLOSED UNDER
21 SUBSECTION (A) OF THIS SECTION, THE DEPARTMENT SHALL RECEIVE A WRITTEN
22 AGREEMENT FROM THE PARTNERING ENTITY TO MAINTAIN THE CONFIDENTIALITY
23 OF THE INFORMATION.

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

26 (I) OBTAIN APPROVAL FROM THE COMMITTEE AT THE
27 RESEARCH INSTITUTION THAT NORMALLY REVIEWS RESEARCH PROJECTS FOR THE
28 PROTECTION OF HUMAN SUBJECTS ESTABLISHED IN ACCORDANCE WITH TITLE 45
29 OF THE CODE OF FEDERAL REGULATIONS; AND

30 (II) PROVIDE DOCUMENTATION TO THE DEPARTMENT THAT
31 DEMONSTRATES, TO THE DEPARTMENT'S SATISFACTION, THAT THE RESEARCH
32 ENTITY HAS ESTABLISHED PROCEDURES AND THE ABILITY TO MAINTAIN THE
33 CONFIDENTIALITY OF THE DISCLOSED INFORMATION.

1 **18-1206.**

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

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

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

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

9 (III) BE FURTHER DISCLOSED;

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

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

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

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

26 **18-1207.**

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

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