

# SENATE BILL 584

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CF HB 703

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By: **Senators Gile and Elfreth**

Introduced and read first time: February 6, 2023

Assigned to: Finance

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## 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:

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EXPLANATION: CAPITALS INDICATE MATTER ADDED TO EXISTING LAW.

[Brackets] indicate matter deleted from existing law.



1 **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.**9 **(2) “PARKINSONISMS” INCLUDES MULTIPLE SYSTEM ATROPHY,**  
10 **DEMENTIA WITH LEWY BODIES, CORTICOBASAL DEGENERATION, AND PROGRESSIVE**  
11 **SUPRANUCLEAR PALSY.**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;27 (2) Determine what data shall be collected and be stored in a Parkinson’s  
28 Disease Registry and the methods to ensure the privacy and confidentiality of data collected  
29 and stored in the registry; and

1           (3) Advise the Department on Parkinson's disease and maintaining a  
2 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;

11                  (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:**

1           **(1) IDENTIFY CATEGORIES OF DATA TO BE COLLECTED FOR THE**  
2 **REGISTRY RELATED TO:**

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.**

14                   **(2) THE DEPARTMENT SHALL IMPLEMENT A CODING SYSTEM THAT**  
15 **REMOVES ANY PERSONALLY IDENTIFIABLE INFORMATION OF AN INDIVIDUAL FROM**  
16 **COLLECTED DATA.**

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:**

23                   **(I) NOTIFY, IN WRITING AND ORALLY, ALL INDIVIDUALS IN THE**  
24 **STATE DIAGNOSED WITH PARKINSON'S DISEASE OR RELATED PARKINSONISMS**  
25 **ABOUT THE CREATION OF THE REGISTRY, DATA COLLECTION ASSOCIATED WITH**  
26 **THE REGISTRY, AND THE RIGHT TO OPT OUT OF PARTICIPATION IN THE REGISTRY;**  
27 **AND**

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

1           **(2) (I) AN INDIVIDUAL WITH PARKINSON’S DISEASE OR RELATED**  
2 **PARKINSONISMS MAY OPT OUT OF PARTICIPATING IN THE REGISTRY BY**  
3 **SUBMITTING WRITTEN NOTICE TO THE DEPARTMENT.**

4           **(II) IF AN INDIVIDUAL OPTS OUT OF PARTICIPATION IN THE**  
5 **REGISTRY, THE DEPARTMENT:**

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

8                   **2. MAY NOT RECORD ANY ADDITIONAL INFORMATION**  
9 **ABOUT THE INDIVIDUAL.**

10           **(D) THE DEPARTMENT MAY:**

11                   **(1) CREATE, REVIEW, AND REVISE A LIST OF DATA POINTS REQUIRED**  
12 **AS PART OF MANDATED PARKINSON’S DISEASE REPORTING UNDER THIS SECTION,**  
13 **INCLUDING NECESSARY TRIGGERING DIAGNOSTIC CONDITIONS THAT ARE**  
14 **CONSISTENT WITH THE LATEST INTERNATIONAL STATISTICAL CLASSIFICATION OF**  
15 **DISEASES AND RELATED HEALTH PROBLEMS; AND**

16                   **(2) IMPLEMENT THE COLLECTION OF DATA POINTS ON THE LIST**  
17 **CREATED UNDER ITEM (1) OF THIS SUBSECTION THROUGH A BULLETIN, OR SIMILAR**  
18 **INSTRUCTION, TO NURSE PRACTITIONERS, PHYSICIANS, AND PHYSICIAN**  
19 **ASSISTANTS.**

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**

28                   **(3) DIRECTLY TO THE STATE BOARD OF NURSING AND THE STATE**  
29 **BOARD OF PHYSICIANS.**

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:

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

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.

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

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;

- 1           **(3) ADDRESS;**  
2           **(4) ORGANIZATIONAL AFFILIATION;**  
3           **(5) DATES OF ACCESS; AND**  
4           **(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.**

9           **(A) ON OR BEFORE DECEMBER 1 EACH YEAR, BEGINNING IN 2023, THE**  
10 **ADVISORY COMMITTEE SHALL REPORT TO THE SECRETARY OF HEALTH AND, IN**  
11 **ACCORDANCE WITH § 2-1257 OF THE STATE GOVERNMENT ARTICLE, THE SENATE**  
12 **FINANCE COMMITTEE AND THE HOUSE HEALTH AND GOVERNMENT OPERATIONS**  
13 **COMMITTEE ON THE REGISTRY AND THE PREVALENCE OF PARKINSON'S DISEASE IN**  
14 **THE STATE.**

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.**