

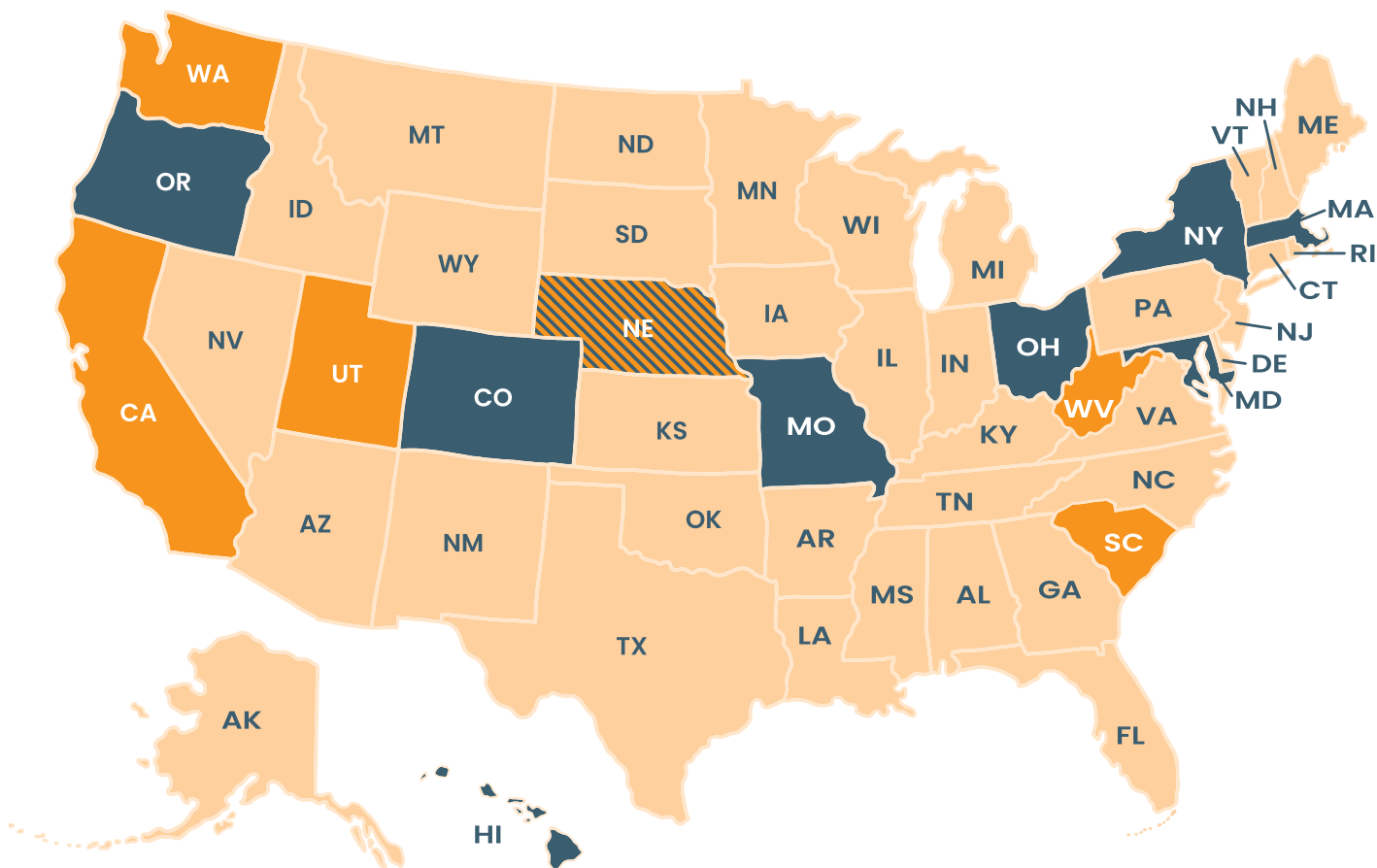
1State Reg One Pager blue[46].pdf

Uploaded by: Julia Pitcher

Position: FAV

Parkinson's Research Registries

- States with registries
- Targeted states for 2023



Current Registries

✓ California

Established in 2017. Expanded in 2021 to include other neurodegenerative diseases.

✓ Nebraska

Established in 1996, but still a paper/manual registry. Legislation expected in 2023 to increase state funding to modernize the existing registry.

✓ South Carolina

Passed registry legislation in 2022 and will be housed within the Medical University of South Carolina (MUSC). Establishing Advisory Committee members now, and plans for infrastructure coming within the next year.

✓ Utah

Established in 2015 and housed within the University of Utah Department of Neurology.

✓ Washington

Voluntary registry exists, but information pertaining to metrics or if information is reported to CDC is not clear.

✓ West Virginia

Passed registry legislation in 2022 and will be housed within WVU Rockefeller Neuroscience Institute. Establishing Advisory Committee members now, and plans for infrastructure coming within the next year.

Research Registries

A disease registry is a special database that contains information about people diagnosed with a specific type of disease. Registries can be used to closely monitor the healthcare process to detect potential problems and to, ultimately, achieve better results for patients. For example, patient engagement has often been a struggle for providers.

Creation of a state registry database will feed deidentified patient information upon diagnosis, to the state department of health, and further to the CDC for use in research, for planning for health care requirements, and for education of health care providers.

Passage of this legislation to create a statewide population-based registry will be used to measure the incidence and prevalence of Parkinson's disease.

Surprisingly, little is known about how PD is distributed among different population groups and whether the patterns of the disease are changing over time.

This legislation will expand our understanding of Parkinson's disease to ultimately improve the lives of those affected.

- + The data will help identify high-risk groups, support patient contact studies, and serve as a valuable data resource to prevent and optimally manage Parkinson's disease.
- + To determine incidence and prevalence of Parkinson's disease more accurately by state.
- + The data will help researchers study patterns of Parkinson's disease over time.
- + Help determine if certain regions of the state that use more pesticides have higher incidents of Parkinson's. Studies have shown a correlation between higher pesticide use and increases in Parkinson's cases.
- + Improve our understanding of the link between Parkinson's and military service since a larger portion of the veteran's community has Parkinson's compared to the general population.

Why We Advocate

We advocate because the government plays a pivotal role in accelerating research toward prevention and a cure, and ensuring quality of life for those already living with Parkinson's and their families. Parkinson's occurs when brain cells that make dopamine—a chemical that coordinates movement—stop working or die. Currently, there is no treatment to prevent, slow, stop, or reverse disease progression, nor is there a cure. There is no one exact cause of Parkinson's, and researchers believe it is likely caused by a combination of genetic factors and environmental factors. Known primarily as a "movement disorder," the most known traits of Parkinson's are tremor, slowness, walking and balance problems, as well as constipation, depression, memory problems, dementia, and more. Parkinson's symptoms worsen over time.



1 million+

people in the U.S. live with Parkinson's, including more than 100,000 veterans



\$52 billion

is spent by the U.S. every year on Parkinson's; half is paid for by the federal government



\$80 billion

is what the annual cost will grow to by 2037, with more than \$40 billion shouldered by the federal government



Fastest-growing

Parkinson's is the fastest -growing brain disease (second most common after Alzheimer's)



90,000+

people are diagnosed with Parkinson's each year



The Michael J. Fox Foundation for Parkinson's Research The Michael J. Fox Foundation for Parkinson's Research (MJFF) has a single, urgent goal: Eliminate Parkinson's in our lifetime. We have funded over \$1.5 billion in research since our founding over 20 years ago. MJFF advocates at the federal and state level for funding and policies that accelerate the search for a cure and improve quality of life for people with Parkinson's as well as their families and caregivers. MJFF is here until Parkinson's isn't.

Stay in touch with us by visiting the [State Action Center](#) or emailing policy@michaeljfox.org.

MD SB 584 - PD Registry - Letter of Support.pdf

Uploaded by: Julia Pitcher

Position: FAV



March 10, 2023

The Honorable Melanie Griffith Chairwoman
Senate Finance Committee
3 East, Miller House Office Building
Annapolis, MD 21401

RE: SB 584 – Maryland Parkinson's Disease Registry (SUPPORT + SPONSOR AMENDMENTS)

Dear Chairwoman Griffith and members of the committee,

The Michael J. Fox Foundation for Parkinson's Research was founded in 2000 and has been singularly dedicated to finding a cure for Parkinson's Disease (PD) through an aggressively funded research agenda and to ensuring the development of improved therapies for those living with PD today.

We offer our full support for HB 703 which would establish a Parkinson's Disease Registry in Maryland. We are also in full support of the sponsor amendments to establish that the data collection is to begin with the State's Health Information Exchange and deposit that data to the Department of Health.

A Maryland Parkinson's Disease registry, along with those already established in California, Utah, Washington, and most recently West Virginia and South Carolina could truly power significant progress toward new treatments, and ultimately a cure for Parkinson's patients. The registry would provide data on the incidence of the disease and its various patterns in the state, including potential geographic clusters and environmental exposures. Patient registries can provide a real-world view of clinical practice, patient outcomes, safety, and comparative effectiveness. Registry data can also inform policymakers about health care equity disparities and the influences of social determinants of health.

Parkinson's disease is the second most common and fastest growing neurological disease in the world and the number of people with PD is expected to double by 2040. The annual cost of Parkinson's nationally is at least \$52 billion and that will rise to nearly \$80 billion by 2037.¹

The direct and indirect costs to care for the over 19,000 people living with PD in Maryland is \$950 million per year – finding new treatments and ultimately a cure would save tens of millions of dollars each year.²

¹ <https://www.michaeljfox.org/news/study-finds-parkinsons-52-billion-economic-burden-double-previous-estimates>

² <https://www.lewin.com/resources/publications/economic-burden-parkinsons.html>

Establishing a state research collection registry will feed into the Center for Disease Control's National Neurological Conditions Surveillance System which tracks the incidence and prevalence of many neurologic disorders, including Parkinson's.

Researchers around the globe will be able to take state-based data to:

- Help identify high-risk groups, support patient contact studies, and serve as a valuable data resource to prevent and optimally manage Parkinson's disease.
- To determine incidence and prevalence of Parkinson's disease more accurately by state.
- The data will help researchers study patterns of Parkinson's disease over time.
- Help determine if certain regions of the state that use more pesticides have higher a higher incidence of Parkinson's. Studies have shown a correlation between higher pesticide use and increases in Parkinson's cases.
- Improve our understanding of the link between Parkinson's and military service since a larger portion of the veteran's community has Parkinson's compared to the general population.
- Privacy of individual patients is protected rigorously within registries, compliant with the Health Insurance Portability and Accountability Act (HIPAA) and other federal and state privacy laws.

When properly designed, a Parkinson's registry can expand in the future to collect data on other neurological diseases. Given the known, and unknown, neurological impact of COVID-19, a state registry could provide data critical for treatments of future coronaviruses.

The registry data would also provide insight into Parkinson's 'clusters' in the state and would enable greater scientific understanding of exposure of firefighters and other first responders to chemicals, toxins, heavy metals, and other possible environmental factors that may be Parkinson's triggers.

On behalf of the foundation and the patients we support, we urge a **favorable vote on SB 584**. Thank you for your time and consideration, please don't hesitate to contact me at jpitcher@michaeljfox.org or 202-638-4101, ext. 441.

Sincerely,

A handwritten signature in brown ink that reads "Julia Pitcher". The signature is written in a cursive, flowing style.

Julia L. Pitcher, JD
Director of State Government Relations
The Michael J. Fox Foundation for Parkinson's Research

SB 584 Public Health Parkinson's Disease Registry.

Uploaded by: Larry Zarzecki

Position: FAV



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facebook.com/aarpm

SB 584 Public Health – Parkinson’s Disease Registry – Established
Senate Finance Committee
FAVORABLE
March 10, 2023

Good afternoon Chair Griffith and members of the Senate Finance Committee. I am Larry Zarzecki, Health Care Advocate for AARP Maryland. As you know, AARP Maryland is one of the largest membership-based organizations in the country. AARP Maryland support SB 584. We thank Senator Gile for championing this important bill.

AARP is a nonpartisan, nonprofit, nationwide organization that fights for the issues that matter most to families such as healthcare, employment and income security, retirement planning, affordable utilities and protection from financial abuse.

SB 584 establishes a Parkinson’s Disease Registry and a Parkinson’s Disease Registry Advisory Committee to establish a system for the collection and dissemination of information determining the incidence and prevalence of “Parkinson’s Disease. An individual with Parkinson’s may opt out of participating in the registry. A nurse practitioner, physician, or physician assistant who diagnoses patients with Parkinson’s disease and related to Parkinson Disease must report each case to the registry. The registry will be housed at the Maryland Department of Health.

Parkinson's disease is a chronic motor system disorder that normally affects patients over the age of 50. However, young-onset Parkinson's disease occurs in those aged 21-45. Common symptoms include tremors, muscle rigidity, slowness of movement, impaired balance and a shuffling gait.

The registry is a database that can be utilized for research on Parkinson's, for planning for health care requirements and for education of health care providers. This bill if passed will create a Parkinson Disease registry that will collect information about the disease and will be used by researchers. If enacted, researchers could use that data to identify patterns, look at trends across a population diverse in race, ethnicity, socioeconomic status and history of exposure to occupational and environmental toxins to help Marylanders who have Parkinson Disease.

For these reasons we respectfully ask the Committee for a favorable report on SB 584. For follow up or questions, please contact me at tbresnahan@aarp.org or by calling 410-302-8451.



DG_Final Written Testimony_SB584.pdf

Uploaded by: Senator Gile

Position: FAV



THE SENATE OF MARYLAND
ANNAPOLIS, MARYLAND 21401

**Testimony in Support of SB584
Public Health – Parkinson’s Disease Registry – Established**

Madame Chair, Madame Vice Chair, and Fellow Members of the Senate Finance Committee:

SB584 establishes a voluntary Parkinson's Disease Registry database which will feed deidentified patient information upon diagnosis to the state Department of Health (DoH), and further to the Center for Disease Control for use in research, for planning for health care requirements, and for education of health care providers.

Background

Parkinson’s disease (PD) is a chronic neurodegenerative disease or chronic motor system disorder that gradually worsens over time. There is no treatment to slow, stop, or reverse the progression, nor is there a cure. Common symptoms include tremors, muscle rigidity, slowness of movement, impaired balance, and a shuffling gait. More than one million Americans, including 110,000 military veterans live with PD.

Beyond its impact on the people living with PD and their loved ones, the disease is costly to our society with an economic burden of \$52 billion each year. The amount spent on research of the disease pales in comparison to the amount spent to care for people with Parkinson’s with the federal government spending \$28 billion every year on care and only \$180 million on research.

Solution

The registry created by SB584 will expand our understanding of PD to ultimately improve the lives of those affected. The registry will help:

- Identify high-risk groups, support patient contact studies, and serve as a valuable data resource to prevent and optimally manage PD.
- Researchers study patterns of PD over time.
- Determine if certain regions of the state that use more pesticides have higher incidents of Parkinson’s.

- Improve our understanding of the link between Parkinson's and military service since a larger portion of the veteran's community has Parkinson's compared to the general population.

Six states have already created a state PD registry include California, Washington, and West Virginia.

Amendment & Reprint

I am offering an amendment to the bill that will drastically reduce the fiscal impact of the bill as outlined in the Fiscal Note. Over the interim, the DoH, Chesapeake Regional Information System for our Patients (CRISP), and other stakeholders met pursuant to the bill passed on this topic in the last Legislative Session, SB740. Representatives from CRISP offered to integrate data collection on PD into their existing system, which means the DoH will not need to create a new database to implement the registry. A final report that reflects this arrangement is expected to be published by DoH imminently. The amendment and the accompanied reprint that I am offering reflects this agreement. Because the DoH would not need to collect the data for the registry, no additional staff would need to be hired and no major infrastructure would need to be established to create the registry. CRISP has agreed to take on these responsibilities at no significant cost to the state. Upon adoption of the amendment, I expect a revised Fiscal Note to show a drastically reduced fiscal impact than the original one based on the existing text of the bill.

For these reasons, I respectfully request a favorable report with amendments on Senate Bill 584.

SB0584-553426-01.pdf

Uploaded by: Senator Gile

Position: FAV



SB0584/553426/1

AMENDMENTS
PREPARED
BY THE
DEPT. OF LEGISLATIVE
SERVICES

27 FEB 23
17:19:35

BY: Senator Gile
(To be offered in the Finance Committee)

AMENDMENTS TO SENATE BILL 584
(First Reading File Bill)

AMENDMENT NO. 1

On page 1, in line 4, strike the second “Department” and substitute “State-designated health information exchange”; in line 5, after the first “Registry” insert “and report certain data to the Department on request”; in line 12, after “Section” insert “4-302.3(g).”; in the same line, after “18-1201” insert a comma; and in line 22, strike “18-1210” and substitute “18-1214”.

AMENDMENT NO. 2

On page 2, after line 1, insert:

“4-302.3.

(g) (1) The State-designated health information exchange shall:

(i) Participate in the advisory committee established under § 13-4306(a)(1) of this article; [and]

(ii) Maintain a data set for the Maryland Commission on Health Equity and provide data from the data set consistent with the parameters defined by the advisory committee ESTABLISHED UNDER § 13-4306(A)(1) OF THIS ARTICLE; AND

(III) COLLECT DATA FOR THE PARKINSON’S DISEASE REGISTRY UNDER TITLE 18, SUBTITLE 12 OF THIS ARTICLE.

(2) If approved by the Maryland Commission on Health Equity, the State-designated health information exchange may use the data set maintained under paragraph [(1)] (1)(II) of this subsection to improve health outcomes for patients.”.

On page 3, in line 23, after “(A)” insert “(1)”; in the same line, strike “THE” and substitute “BEGINNING OCTOBER 1, 2024, THE”; and after line 25, insert:

“(2) (I) ON REQUEST OF THE DEPARTMENT, THE STATE-DESIGNATED HEALTH INFORMATION EXCHANGE SHALL REPORT THE DATA FOR THE REGISTRY TO THE DEPARTMENT IN A FORMAT DETERMINED BY THE DEPARTMENT.

(II) THE DATA REPORTED UNDER SUBPARAGRAPH (I) OF THIS PARAGRAPH SHALL INCLUDE DATA AT THE PATIENT-LEVEL AND AT THE AGGREGATE-LEVEL.”.

On page 3 in line 23, on page 5 in lines 5 and 20, and on page 6 in lines 2 and 3, in each instance, strike “DEPARTMENT” and substitute “STATE-DESIGNATED HEALTH INFORMATION EXCHANGE”.

On page 4, in lines 17 and 21, in each instance, after “THE” insert “STATE-DESIGNATED HEALTH INFORMATION EXCHANGE AND THE”; strike beginning with the colon in line 22 down through “NOTIFY” in line 23 and substitute “NOTIFY”; in lines 26 and 27, strike “; AND” and substitute a period; and strike in their entirety lines 28 and 29.

On page 5, strike beginning with “AN” in line 1 down through “DEPARTMENT” in line 3 and substitute “THE STATE-DESIGNATED HEALTH INFORMATION EXCHANGE SHALL ALLOW AN INDIVIDUAL WITH PARKINSON’S DISEASE OR RELATED PARKINSONISMS TO OPT OUT OF PARTICIPATING IN THE REGISTRY IN

ACCORDANCE WITH HEALTH INFORMATION REGULATIONS ADOPTED BY THE MARYLAND HEALTH CARE COMMISSION UNDER COMAR 10.25.18”.

On page 7, after line 20, insert:

“(C) IF INFORMATION PROVIDED UNDER THIS SUBTITLE IS PROVIDED CONFIDENTIALLY, THE PROVISION OF THE INFORMATION MAY NOT:

(1) EXPOSE ANY PERSON TO LIABILITY FOR PROVIDING THE INFORMATION; AND

(2) BE CONSIDERED A WAIVER OF ANY PRIVILEGE OR A VIOLATION OF A CONFIDENTIAL RELATIONSHIP.

(D) AN INDIVIDUAL WHOSE INFORMATION IS IN THE REGISTRY SHALL HAVE ACCESS TO THE INDIVIDUAL’S INFORMATION.”.

On page 8, after line 7, insert:

“18-1210.

FOR EACH OF FISCAL YEARS 2025 THROUGH 2029, THE GOVERNOR SHALL INCLUDE IN THE ANNUAL BUDGET BILL AN APPROPRIATION SUFFICIENT TO ENSURE THE PROPER DEVELOPMENT AND MAINTENANCE OF THE REGISTRY AND ADEQUATE STAFFING TO IMPLEMENT AND MAINTAIN THE REGISTRY.

18-1211.

THE DEPARTMENT MAY INSPECT A REPRESENTATIVE SAMPLE OF THE MEDICAL RECORDS OF PATIENTS DIAGNOSED OR TREATED, INCLUDING

(Over)

PATIENTS ADMITTED FOR TREATMENT, FOR PARKINSON'S DISEASE AND RELATED PARKINSONISMS AT HOSPITALS AND OTHER HEALTH CARE FACILITIES THAT PROVIDE TREATMENT FOR PARKINSON'S DISEASE AND RELATED PARKINSONISMS TO ENSURE COMPLIANCE WITH THE REPORTING REQUIREMENTS ESTABLISHED UNDER THIS SUBTITLE.

18-1212.

(A) ON OR BEFORE OCTOBER 1, 2029, THE DEPARTMENT AND THE ADVISORY COMMITTEE SHALL CONDUCT A REVIEW OF THE REGISTRY, INCLUDING:

(1) HOW THE REGISTRY IS BEING USED; AND

(2) WHETHER THE REGISTRY IS FULFILLING ITS INTENDED PURPOSE.

(B) FOLLOWING THE REVIEW OF THE REGISTRY CONDUCTED UNDER SUBSECTION (A) OF THIS SECTION, THE DEPARTMENT SHALL DEVELOP RECOMMENDATIONS ON ANY CHANGES DETERMINED TO BE NECESSARY TO UPDATE THE REGISTRY.

18-1213.

THE DEPARTMENT SHALL CREATE AND MAINTAIN A PUBLICLY AVAILABLE WEBSITE THAT INCLUDES INFORMATION RELATED TO THE REGISTRY, INCLUDING:

(1) A YEARLY PROGRAM SUMMARY; AND

(2) ANY OTHER RELEVANT INFORMATION RELATED TO THE REGISTRY DETERMINED TO BE NECESSARY BY THE ADVISORY COMMITTEE.;

in line 8, strike “**18-1210.**” and substitute “**18-1214.**”; in line 10, strike “**ADVISORY COMMITTEE**” and substitute “**DEPARTMENT**”; strike beginning with “**THE**” in line 10 down through “**ARTICLE,**” in line 11; strike beginning with the first “**THE**” in line 13 down through “**STATE**” in line 14 and substitute “**, IN ACCORDANCE WITH § 2-1257 OF THE STATE GOVERNMENT ARTICLE, THE FOLLOWING INFORMATION:**”

(1) THE INCIDENCE AND PREVALENCE OF PARKINSON’S DISEASE IN THE STATE BY COUNTY;

(2) THE NUMBER OF MEDICAL RECORDS THAT HAVE BEEN REPORTED TO AND INCLUDED IN THE REGISTRY;

(3) DEMOGRAPHIC INFORMATION FROM THE REGISTRY, SUCH AS PATIENTS BY AGE, GENDER, AND RACE, WITHOUT THE DISCLOSURE OF PERSONALLY IDENTIFIABLE INFORMATION; AND

(4) ANY OTHER INFORMATION THE DEPARTMENT DETERMINES IS RELEVANT TO THE REGISTRY AND PARKINSON’S DISEASE IN THE STATE.

SB584 FinalReprint.pdf

Uploaded by: Senator Gile

Position: FAV

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SENATE BILL 584

J1

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~~ State-designated health information exchange to
collect certain data for the

5 Registry and report certain data to the Department on request; 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 ~~4-302.3(g)~~, 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~~ 18-1214

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:

2

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1

Article - Health - General

4-302.3.

(g) (1) The State-designated health information exchange shall:

(i) Participate in the advisory committee established under § 13-4306(a)(1) of this article; [and]

(ii) Maintain a data set for the Maryland Commission on Health Equity and provide data from the data set consistent with the parameters defined by the advisory committee ESTABLISHED UNDER § 13-4306(A)(1) OF THIS ARTICLE; AND

(III) COLLECT DATA FOR THE PARKINSON'S DISEASE REGISTRY UNDER TITLE 18, SUBTITLE 12 OF THIS ARTICLE.

(2) If approved by the Maryland Commission on Health Equity, the State-designated health information exchange may use the data set maintained under paragraph [(1)] (1)(II) of this subsection to improve health outcomes for patients.

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

3

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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) (1) ~~THE BEGINNING OCTOBER 1, 2024, THE DEPARTMENT~~**
24 **STATE-DESIGNATED HEALTH INFORMATION EXCHANGE SHALL COLLECT DATA FOR THE REGISTRY,**
25 **INCLUDING DATA ON THE INCIDENCE OF PARKINSON'S DISEASE IN THE STATE AND**
RELATED EPIDEMIOLOGICAL DATA.

(2) (I) ON REQUEST OF THE DEPARTMENT, THE
STATE-DESIGNATED HEALTH INFORMATION EXCHANGE SHALL REPORT THE DATA FOR THE REGISTRY TO
THE DEPARTMENT IN A FORMAT DETERMINED BY THE DEPARTMENT.

(II) THE DATA REPORTED UNDER SUBPARAGRAPH (I) OF THIS
PARAGRAPH SHALL INCLUDE DATA AT THE PATIENT-LEVEL AND AT THE
AGGREGATE-LEVEL.

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

4

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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 STATE-DESIGNATED HEALTH INFORMATION EXCHANGE**
 18 **AND THE ADVISORY**
 19 **COMMITTEE, SHALL ESTABLISH A SYSTEM FOR THE COLLECTION OF DATA FOR THE**
 20 **REGISTRY AND DISSEMINATION OF INFORMATION DETERMINING THE INCIDENCE**
 21 **AND PREVALENCE OF PARKINSON'S DISEASE AND RELATED PARKINSONISMS.**

22 **(C) (1) THE DEPARTMENT, IN CONSULTATION WITH THE STATE-DESIGNATED HEALTH INFORMATION**
 23 **EXCHANGE AND THE ADVISORY**
 24 **COMMITTEE, SHALL**

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

31 ~~(II)~~ **PROVIDE AN OPPORTUNITY TO OPT OUT OF PARTICIPATION**
 32 **IN THE REGISTRY.**

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5

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~~ THE STATE-DESIGNATED HEALTH INFORMATION EXCHANGE
SHALL ALLOW AN INDIVIDUAL WITH PARKINSON'S DISEASE OR RELATED PARKINSONISMS TO OPT OUT OF
PARTICIPATING IN THE
REGISTRY IN ACCORDANCE WITH HEALTH INFORMATION REGULATIONS ADOPTED BY THE MARYLAND HEALTH CARE
COMMISSION
UNDER COMAR 10.25.18.

4 (II) IF AN INDIVIDUAL OPTS OUT OF PARTICIPATION IN THE
 5 REGISTRY, THE ~~DEPARTMENT~~ STATE-DESIGNATED HEALTH INFORMATION EXCHANGE:

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~~ STATE-DESIGNATED HEALTH INFORMATION
EXCHANGE 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

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1 RELATED PARKINSONISMS TO THE REGISTRY IN A FORMAT DETERMINED BY THE
2 ~~DEPARTMENT~~ STATE-DESIGNATED HEALTH INFORMATION EXCHANGE.

3 (2) ~~THE DEPARTMENT~~ STATE-DESIGNATED HEALTH INFORMATION EXCHANGE 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:

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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.

(C) IF INFORMATION PROVIDED UNDER THIS SUBTITLE IS PROVIDED
CONFIDENTIALLY, THE PROVISION OF THE INFORMATION MAY NOT:

(1) EXPOSE ANY PERSON TO LIABILITY FOR PROVIDING THE
INFORMATION; AND

(2) BE CONSIDERED A WAIVER OF ANY PRIVILEGE OR A VIOLATION OF A
CONFIDENTIAL RELATIONSHIP.

(D) AN INDIVIDUAL WHOSE INFORMATION IS IN THE REGISTRY SHALL
HAVE ACCESS TO THE INDIVIDUAL'S 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;

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- 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.

18-1210.

FOR EACH OF FISCAL YEARS 2025 THROUGH 2029, THE GOVERNOR SHALL INCLUDE IN THE ANNUAL BUDGET BILL AN APPROPRIATION SUFFICIENT TO ENSURE THE PROPER DEVELOPMENT AND MAINTENANCE OF THE REGISTRY AND ADEQUATE STAFFING TO IMPLEMENT AND MAINTAIN THE REGISTRY.

18-1211.

THE DEPARTMENT MAY INSPECT A REPRESENTATIVE SAMPLE OF THE MEDICAL RECORDS OF PATIENTS DIAGNOSED OR TREATED, INCLUDING PATIENTS ADMITTED FOR TREATMENT, FOR PARKINSON'S DISEASE AND RELATED PARKINSONISMS AT HOSPITALS AND OTHER HEALTH CARE FACILITIES THAT PROVIDE TREATMENT FOR PARKINSON'S DISEASE AND RELATED PARKINSONISMS TO ENSURE COMPLIANCE WITH THE REPORTING REQUIREMENTS ESTABLISHED UNDER THIS SUBTITLE.

18-1212.

(A) ON OR BEFORE OCTOBER 1, 2029, THE DEPARTMENT AND THE ADVISORY COMMITTEE SHALL CONDUCT A REVIEW OF THE REGISTRY, INCLUDING:

- (1) HOW THE REGISTRY IS BEING USED; AND
- (2) WHETHER THE REGISTRY IS FULFILLING ITS INTENDED PURPOSE.

(B) FOLLOWING THE REVIEW OF THE REGISTRY CONDUCTED UNDER SUBSECTION (A) OF THIS SECTION, THE DEPARTMENT SHALL DEVELOP RECOMMENDATIONS ON ANY CHANGES DETERMINED TO BE NECESSARY TO UPDATE THE REGISTRY.

18-1213.

THE DEPARTMENT SHALL CREATE AND MAINTAIN A PUBLICLY AVAILABLE WEBSITE THAT INCLUDES INFORMATION RELATED TO THE REGISTRY, INCLUDING:

- (1) A YEARLY PROGRAM SUMMARY; AND
- (2) ANY OTHER RELEVANT INFORMATION RELATED TO THE REGISTRY DETERMINED TO BE NECESSARY BY THE ADVISORY COMMITTEE.

8 ~~18-1210.~~ **18-1214.**

9 (A) ON OR BEFORE DECEMBER 1 EACH YEAR, BEGINNING IN 2023, THE
10 ~~ADVISORY COMMITTEE~~ DEPARTMENT 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~~ , IN ACCORDANCE WITH § 2-1257 OF THE STATE GOVERNMENT ARTICLE, THE FOLLOWING
INFORMATION:

(1) THE INCIDENCE AND PREVALENCE OF PARKINSON'S DISEASE IN
THE STATE BY COUNTY;

(2) THE NUMBER OF MEDICAL RECORDS THAT HAVE BEEN REPORTED TO
AND INCLUDED IN THE REGISTRY;

(3) DEMOGRAPHIC INFORMATION FROM THE REGISTRY, SUCH AS
PATIENTS BY AGE, GENDER, AND RACE, WITHOUT THE DISCLOSURE OF PERSONALLY
IDENTIFIABLE INFORMATION; AND

(4) ANY OTHER INFORMATION THE DEPARTMENT DETERMINES IS
RELEVANT TO THE REGISTRY AND PARKINSON'S DISEASE IN 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.

2 - X - SB 584 - FIN - MDH - LOI.docx.pdf

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Position: INFO



DEPARTMENT OF HEALTH

Wes Moore, Governor · Aruna Miller, Lt. Governor · Laura Herrera Scott, M.D., M.P.H., Secretary

March 10, 2023

The Honorable Melony Griffith
Chair, Senate Finance Committee
3 East, Miller Senate Office Building
Annapolis, Maryland 21401

RE: Senate Bill 584 - Public Health – Parkinson’s Disease Registry – Established - Letter of Information

Dear Chair Griffith and Committee Members:

The Maryland Department of Health (MDH) respectfully submits this letter of information for Senate Bill (SB) 584 - Public Health – Parkinson’s Disease Registry – Established. SB 584 establishes a Parkinson’s Disease Registry within MDH and charges MDH, in consultation with the Parkinson’s Disease Registry Advisory Committee, to establish a system for collecting data for the registry and disseminating information about Parkinson’s disease and Parkinsonism in the state.

As written, MDH will be responsible for creating, implementing, and maintaining a Parkinson’s disease registry program, managing data requests, conducting data analysis, and consulting regularly with the Advisory Committee. It is MDH’s understanding that the bill sponsor and advocates plan to put forward amendments to the bill that would potentially shift some of the duties and responsibilities away from MDH. However, with these amendments, it is MDH’s belief that the responsibility to operate and fund the registry will still reside with MDH. We look forward to reviewing the amendments and are open to continued conversations.

If you would like to discuss this further, please do not hesitate to contact Megan Peters, Acting Director of Governmental Affairs at megan.peters@maryland.gov or (410) 260-3190.

Sincerely,

Laura Herrera Scott, M.D., M.P.H.
Secretary