

#### SB0584/553426/1

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 "<u>State-designated health information exchange</u>"; in line 5, after the first "Registry" insert "<u>and report certain data to the Department on request</u>"; in line 12, after "Section" insert "<u>4–302.3(g)</u>."; in the same line, after "18–1201" insert a comma; and in line 22, strike "18–1210" and substitute "<u>18–1214</u>".

#### AMENDMENT NO. 2

On page 2, after line 1, insert:

"<u>4–302.3.</u>

(g) (1) <u>The State-designated health information exchange shall:</u>

(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.

AMENDMENTS PREPARED BY THE DEPT. OF LEGISLATIVE SERVICES

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(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.".

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On page 3, in line 23, after "(A)" insert "(1)"; in the same line, strike "THE" and substitute "<u>BEGINNING OCTOBER 1, 2024, THE</u>"; and after line 25, insert:

# "(2) (1) 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 "<u>STATE-</u> <u>DESIGNATED HEALTH INFORMATION EXCHANGE AND THE</u>"; strike beginning with the colon in line 22 down through "**NOTIFY**" in line 23 and substitute "<u>NOTIFY</u>"; 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 "<u>THE STATE-DESIGNATED HEALTH INFORMATION</u> <u>EXCHANGE SHALL ALLOW AN INDIVIDUAL WITH PARKINSON'S DISEASE OR</u> <u>RELATED PARKINSONISMS TO OPT OUT OF PARTICIPATING IN THE REGISTRY IN</u> Gile

## 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) <u>BE CONSIDERED A WAIVER OF ANY PRIVILEGE OR A VIOLATION</u> 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:

"<u>18–1210.</u>

# 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.

<u>18–1211.</u>

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

(Over)

SB0584/553426/01 Amendments to SB 584 Page 4 of 5

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 PARKSINSONISMS TO ENSURE COMPLIANCE WITH THE REPORTING REQUIREMENTS ESTABLISHED UNDER THIS SUBTITLE.

<u>18–1212.</u>

(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.

<u>18–1213.</u>

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

(1) <u>A YEARLY PROGRAM SUMMARY; AND</u>

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# (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 "<u>**18–1214.**</u>"; in line 10, strike "**ADVISORY COMMITTEE**" and substitute "<u>**DEPARTMENT**</u>"; 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 "<u>, IN ACCORDANCE WITH § 2–1257</u> <u>**OF THE STATE GOVERNMENT ARTICLE, THE FOLLOWING INFORMATION:**</u>

(1) <u>The incidence and prevalence of Parkinson's disease</u> 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".