

SENATE BILL 188

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CF 3lr2443

By: **Senators Lam, Rosapepe, Salling, Muse, Carozza, Kramer, and Benson**

Introduced and read first time: January 20, 2023

Assigned to: Finance

A BILL ENTITLED

1 AN ACT concerning

2 **Public Health – Rare Disease Advisory Council**

3 FOR the purpose of establishing the Rare Disease Advisory Council to study and make
4 recommendations on matters relating to individuals with rare diseases in the State;
5 and generally relating to the Rare Disease Advisory Council.

6 BY adding to

7 Article – Health – General

8 Section 13–4801 through 13–4804 to be under the new subtitle “Subtitle 48. Rare
9 Disease Advisory Council”

10 Annotated Code of Maryland

11 (2019 Replacement Volume and 2022 Supplement)

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

14 **Article – Health – General**

15 **SUBTITLE 48. RARE DISEASE ADVISORY COUNCIL.**

16 **13–4801.**

17 **THERE IS A RARE DISEASE ADVISORY COUNCIL.**

18 **13–4802.**

19 **(A) THE COUNCIL CONSISTS OF THE FOLLOWING MEMBERS:**

20 **(1) ONE MEMBER OF THE SENATE OF MARYLAND, APPOINTED BY THE**
21 **PRESIDENT OF THE SENATE;**

EXPLANATION: CAPITALS INDICATE MATTER ADDED TO EXISTING LAW.

[Brackets] indicate matter deleted from existing law.



1 **(2) ONE MEMBER OF THE HOUSE OF DELEGATES, APPOINTED BY THE**
2 **SPEAKER OF THE HOUSE;**

3 **(3) THE SECRETARY, OR THE SECRETARY'S DESIGNEE; AND**

4 **(4) THE FOLLOWING MEMBERS, APPOINTED BY THE GOVERNOR:**

5 **(I) ONE REPRESENTATIVE OF AN ACADEMIC RESEARCH**
6 **INSTITUTION THAT RECEIVES GRANT FUNDING FOR RARE DISEASE RESEARCH;**

7 **(II) ONE REPRESENTATIVE OF THE OFFICE OF MINORITY**
8 **HEALTH AND HEALTH DISPARITIES;**

9 **(III) ONE REPRESENTATIVE OF THE MARYLAND MEDICAL**
10 **ASSISTANCE PROGRAM;**

11 **(IV) ONE REPRESENTATIVE OF THE MARYLAND INSURANCE**
12 **ADMINISTRATION;**

13 **(V) ONE GENETICIST LICENSED AND PRACTICING IN THE**
14 **STATE;**

15 **(VI) ONE REGISTERED NURSE OR ADVANCED PRACTICE**
16 **REGISTERED NURSE LICENSED AND PRACTICING IN THE STATE WITH EXPERIENCE**
17 **TREATING RARE DISEASES;**

18 **(VII) ONE PHYSICIAN LICENSED IN THE STATE WITH**
19 **EXPERIENCE TREATING RARE DISEASES;**

20 **(VIII) ONE HOSPITAL ADMINISTRATOR, OR THE DESIGNEE OF A**
21 **HOSPITAL ADMINISTRATOR, FROM A HOSPITAL IN THE STATE THAT PROVIDES CARE**
22 **TO INDIVIDUALS DIAGNOSED WITH A RARE DISEASE;**

23 **(IX) ONE PHARMACIST LICENSED IN THE STATE WITH**
24 **EXPERIENCE DISPENSING DRUGS USED TO TREAT RARE DISEASES;**

25 **(X) TWO INDIVIDUALS WHO HAVE BEEN DIAGNOSED WITH A**
26 **RARE DISEASE;**

27 **(XI) ONE CAREGIVER OF AN INDIVIDUAL WITH A RARE DISEASE;**

1 **(XII) ONE REPRESENTATIVE OF A RARE DISEASE PATIENT**
2 **ORGANIZATION THAT OPERATES IN THE STATE;**

3 **(XIII) ONE REPRESENTATIVE OF THE BIOPHARMACEUTICAL**
4 **INDUSTRY;**

5 **(XIV) ONE REPRESENTATIVE OF A HEALTH INSURANCE CARRIER**
6 **PROVIDING HEALTH INSURANCE COVERAGE IN THE STATE; AND**

7 **(XV) ONE MEMBER OF THE SCIENTIFIC COMMUNITY WHO IS**
8 **ENGAGED IN RARE DISEASE RESEARCH.**

9 **(B) FOR THE APPOINTED MEMBERS OF THE COUNCIL, THE APPOINTMENT**
10 **PROCESS SHALL BE CONDUCTED IN A TRANSPARENT MANNER TO PROVIDE**
11 **INTERESTED INDIVIDUALS AN OPPORTUNITY TO APPLY.**

12 **(C) ALL MEMBERS OF THE COUNCIL MUST BE FULL-TIME RESIDENTS OF**
13 **THE STATE.**

14 **(D) (1) THE TERM OF AN APPOINTED MEMBER IS 3 YEARS.**

15 **(2) IF A VACANCY OCCURS ON THE COUNCIL, THE MEMBERS OF THE**
16 **COUNCIL SHALL APPOINT AN INDIVIDUAL TO FILL THE VACANCY BY MAJORITY**
17 **VOTE.**

18 **(E) (1) THE GOVERNOR SHALL DESIGNATE THE INITIAL CHAIR OF THE**
19 **COUNCIL TO SERVE A TERM OF 3 YEARS.**

20 **(2) THE INITIAL CHAIR DESIGNATED BY THE GOVERNOR MAY NOT**
21 **HOLD A POSITION WITHIN STATE GOVERNMENT.**

22 **(3) AT THE END OF THE TERM OF THE INITIAL CHAIR, THE MEMBERS**
23 **OF THE COUNCIL SHALL DESIGNATE A NEW CHAIR BY MAJORITY VOTE.**

24 **(4) EXCEPT AS PROVIDED IN PARAGRAPH (1) OF THIS SUBSECTION,**
25 **THE TERM OF A CHAIR OF THE COUNCIL IS 2 YEARS.**

26 **(F) THE DEPARTMENT SHALL PROVIDE STAFF FOR THE COUNCIL.**

27 **(G) A MEMBER OF THE COUNCIL:**

28 **(1) MAY NOT RECEIVE COMPENSATION AS A MEMBER OF THE**
29 **COUNCIL; BUT**

(2) IS ENTITLED TO REIMBURSEMENT FOR EXPENSES UNDER THE STANDARD STATE TRAVEL REGULATIONS, AS PROVIDED IN THE STATE BUDGET.

(H) (1) THE INITIAL MEETING OF THE COUNCIL SHALL OCCUR ON OR BEFORE DECEMBER 30, 2024.

(2) ON OR BEFORE OCTOBER 1, 2025, THE COUNCIL SHALL MEET AT LEAST ONCE PER MONTH IN PERSON OR THROUGH AN ONLINE MEETING PLATFORM AT A TIME DESIGNATED BY THE CHAIR.

(3) AFTER OCTOBER 1, 2025, THE COUNCIL SHALL MEET AT LEAST ONCE PER QUARTER IN PERSON OR THROUGH AN ONLINE MEETING PLATFORM AT A TIME DESIGNATED BY THE CHAIR.

13-4803.

(A) THE COUNCIL SHALL:

(1) CONVENE PUBLIC HEARINGS, MAKE INQUIRIES, AND SOLICIT COMMENTS FROM THE PUBLIC TO ASSIST THE COUNCIL WITH A FIRST-YEAR SURVEY OF THE NEEDS OF RARE DISEASE PATIENTS, CAREGIVERS, AND HEALTH CARE PROVIDERS IN THE STATE;

(2) CONSULT WITH EXPERTS ON RARE DISEASES TO DEVELOP POLICY RECOMMENDATIONS TO IMPROVE PATIENT ACCESS TO AND THE QUALITY OF RARE DISEASE SPECIALISTS, AFFORDABLE AND COMPREHENSIVE HEALTH CARE COVERAGE, RELEVANT DIAGNOSTICS, TIMELY TREATMENT, AND OTHER NEEDED SERVICES;

(3) RESEARCH AND MAKE RECOMMENDATIONS TO STATE AGENCIES AND INSURERS THAT PROVIDE SERVICES TO INDIVIDUALS WITH A RARE DISEASE ON THE IMPACT OF PRIOR AUTHORIZATION, COST-SHARING, TIERING, OR OTHER UTILIZATION MANAGEMENT PROCEDURES ON THE PROVISION OF TREATMENT AND CARE FOR PATIENTS;

(4) ESTABLISH BEST PRACTICES AND PROTOCOLS TO INCLUDE IN STATE PLANNING RELATED TO NATURAL DISASTERS AND PUBLIC HEALTH EMERGENCIES OR OTHER EMERGENCY DECLARATIONS TO ENABLE CONTINUITY OF CARE FOR RARE DISEASE PATIENTS AND ENSURE THAT SAFEGUARDS AGAINST DISCRIMINATION FOR RARE DISEASE PATIENTS ARE IN PLACE;

1 **(5) EVALUATE AND MAKE RECOMMENDATIONS TO IMPLEMENT**
2 **NECESSARY IMPROVEMENTS TO STATE NEWBORN SCREENING PROGRAMS;**

3 **(6) EVALUATE AND MAKE RECOMMENDATIONS REGARDING**
4 **COVERAGE OF PRESCRIPTION DRUGS FOR RARE DISEASE PATIENTS ENROLLED IN**
5 **THE MARYLAND MEDICAL ASSISTANCE PROGRAM, TO IMPROVE COVERAGE OF**
6 **DIAGNOSTICS, AND TO FACILITATE ACCESS TO NECESSARY HEALTH CARE**
7 **PROVIDERS WITH EXPERTISE IN THE TREATMENT OF RARE DISEASES;**

8 **(7) PUBLISH A LIST OF EXISTING AND PUBLICLY ACCESSIBLE**
9 **RESOURCES ON RESEARCH, DIAGNOSIS, TREATMENT, AND EDUCATION RELATING TO**
10 **RARE DISEASES ON THE COUNCIL'S WEBSITE;**

11 **(8) IDENTIFY AREAS OF UNMET NEEDS FOR RESEARCH THAT CAN**
12 **INFORM FUTURE STUDIES AND REPORTS BY THE COUNCIL;**

13 **(9) IDENTIFY AND DISTRIBUTE EDUCATIONAL RESOURCES FOR**
14 **HEALTH CARE PROVIDERS TO FOSTER RECOGNITION AND OPTIMIZE TREATMENT OF**
15 **RARE DISEASES IN THE STATE; AND**

16 **(10) RESEARCH AND IDENTIFY BEST PRACTICES TO ENSURE**
17 **CONTINUITY OF CARE FOR RARE DISEASE PATIENTS TRANSITIONING FROM**
18 **PEDIATRIC TO ADULT CARE.**

19 **(B) THE COUNCIL SHALL PROVIDE OPPORTUNITIES FOR THE PUBLIC TO**
20 **HEAR UPDATES AND PROVIDE INPUT ON THE COUNCIL'S ACTIVITIES.**

21 **(C) THE COUNCIL SHALL MAINTAIN A WEBSITE FOR THE PURPOSES OF:**

22 **(1) POSTING MEETING MINUTES AND NOTICES OF UPCOMING**
23 **MEETINGS;**

24 **(2) ALLOWING THE PUBLIC TO SUBMIT COMMENTS TO THE COUNCIL;**
25 **AND**

26 **(3) POSTING A LIST OF RESOURCES AS REQUIRED UNDER**
27 **SUBSECTION (A)(7) OF THIS SECTION.**

28 **(D) (1) THE COUNCIL MAY SOLICIT FUNDS ON ITS BEHALF, INCLUDING BY**
29 **APPLYING FOR AVAILABLE FEDERAL OR STATE GRANTS.**

30 **(2) THE COUNCIL SHALL SET UP A METHOD TO SECURELY HOLD AND**
31 **DISTRIBUTE FUNDS TO SUPPORT THE DUTIES OF THE COUNCIL.**

1 **13-4804.**

2 **(A) ON OR BEFORE DECEMBER 1 EACH YEAR, BEGINNING IN 2024, THE**
3 **COUNCIL SHALL SUBMIT A REPORT TO THE GOVERNOR AND, IN ACCORDANCE WITH**
4 **§ 2-1257 OF THE STATE GOVERNMENT ARTICLE, THE GENERAL ASSEMBLY.**

5 **(B) THE REPORT REQUIRED UNDER SUBSECTION (A) OF THIS SECTION**
6 **SHALL:**

7 **(1) DESCRIBE THE ACTIVITIES OF THE COUNCIL UNDER § 13-4803(A)**
8 **OF THIS SUBTITLE;**

9 **(2) DESCRIBE THE FUNDING SOURCES OF THE COUNCIL, INCLUDING**
10 **GRANTS THAT WERE APPLIED FOR AND ACCEPTED AND THE REMAINING BALANCES**
11 **OF ANY CURRENT GRANTS; AND**

12 **(3) PROVIDE RECOMMENDATIONS ON THE WAYS TO ADDRESS THE**
13 **NEEDS OF INDIVIDUALS LIVING WITH RARE DISEASES IN THE STATE.**

14 SECTION 2. AND BE IT FURTHER ENACTED, That the terms of the members of
15 the Rare Disease Advisory Council appointed by the Governor under § 13-4802 of the
16 Health – General Article, as enacted by Section 1 of this Act, shall expire as follows:

17 (1) four members in 2025;

18 (2) six members in 2026; and

19 (3) six members in 2027.

20 SECTION 3. AND BE IT FURTHER ENACTED, That this Act shall take effect
21 October 1, 2023.