

HOUSE BILL No. 5983

May 10, 2018, Introduced by Reps. Tedder, Hauck, Graves, Howrylak, Kahle, Sheppard, Calley, Hornberger, Brinks, Hammoud, Camilleri, Garrett, Love, Hertel, Maturen and Crawford and referred to the Committee on Health Policy.

A bill to amend 1978 PA 368, entitled
"Public health code,"
(MCL 333.1101 to 333.25211) by adding sections 5135 and 5135a.

THE PEOPLE OF THE STATE OF MICHIGAN ENACT:

1 **SEC. 5135. (1) THE RARE DISEASE ADVISORY COUNCIL IS CREATED**
2 **WITHIN THE DEPARTMENT.**

3 **(2) THE COUNCIL SHALL CONSIST OF THE DIRECTOR OR HIS OR HER**
4 **DESIGNEE AND THE FOLLOWING MEMBERS, APPOINTED BY THE GOVERNOR:**

5 **(A) TWO PHYSICIANS LICENSED UNDER ARTICLE 15, EACH OF WHOM HAS**
6 **EXPERTISE IN TREATING PATIENTS WITH RARE DISEASES AND 1 OF WHOM IS**
7 **A PEDIATRICIAN WHO PROVIDES CARE TO CHILDREN WITH RARE DISEASES.**

8 **(B) ONE REGISTERED PROFESSIONAL NURSE LICENSED UNDER ARTICLE**
9 **15 WHO HAS EXPERTISE IN PROVIDING CARE TO PATIENTS WITH RARE**

1 DISEASES.

2 (C) A REPRESENTATIVE OF THE BIOPHARMACEUTICAL INDUSTRY.

3 (D) TWO REPRESENTATIVES OF HOSPITALS LICENSED UNDER ARTICLE
4 17.

5 (E) A REPRESENTATIVE OF THE HEALTH INSURANCE INDUSTRY.

6 (F) A REPRESENTATIVE OF THE SCIENTIFIC COMMUNITY WHO IS
7 ENGAGED IN RESEARCH ON RARE DISEASES.

8 (G) TWO PARENTS WHO HAVE A CHILD WITH A RARE DISEASE.

9 (H) TWO INDIVIDUALS WHO HAVE A RARE DISEASE.

10 (I) TWO REPRESENTATIVES FROM RARE DISEASE PATIENT
11 ORGANIZATIONS IN THIS STATE.

12 (3) SUBJECT TO SUBSECTION (13), THE GOVERNOR MAY APPOINT
13 ADDITIONAL MEMBERS TO THE COUNCIL THAT THE GOVERNOR CONSIDERS
14 NECESSARY OR APPROPRIATE.

15 (4) THE MEMBERS FIRST APPOINTED TO THE COUNCIL MUST BE
16 APPOINTED WITHIN 90 DAYS AFTER THE EFFECTIVE DATE OF THIS SECTION.

17 (5) MEMBERS OF THE COUNCIL SHALL SERVE FOR TERMS OF 4 YEARS OR
18 UNTIL A SUCCESSOR IS APPOINTED, WHICHEVER IS LATER, EXCEPT THAT OF
19 THE MEMBERS FIRST APPOINTED 3 SHALL SERVE FOR 1 YEAR, 3 SHALL SERVE
20 FOR 2 YEARS, AND 8 SHALL SERVE FOR 3 YEARS.

21 (6) A VACANCY ON THE COUNCIL MUST BE FILLED IN THE SAME MANNER
22 AS THE ORIGINAL APPOINTMENT. AN INDIVIDUAL APPOINTED TO FILL A
23 VACANCY CREATED OTHER THAN BY EXPIRATION OF A TERM MUST BE
24 APPOINTED FOR THE UNEXPIRED TERM OF THE MEMBER WHOM HE OR SHE IS TO
25 SUCCEED IN THE SAME MANNER AS THE ORIGINAL APPOINTMENT.

26 (7) THE GOVERNOR MAY REMOVE A MEMBER OF THE COUNCIL FOR
27 INCOMPETENCE, DERELICTION OF DUTY, MALFEASANCE, MISFEASANCE, OR

1 NONFEASANCE IN OFFICE, OR ANY OTHER GOOD CAUSE.

2 (8) THE DIRECTOR SHALL CALL THE FIRST MEETING OF THE COUNCIL.
3 AT THE FIRST MEETING, THE COUNCIL SHALL ELECT FROM AMONG ITS
4 MEMBERS A CHAIRPERSON AND OTHER OFFICERS AS IT CONSIDERS NECESSARY
5 OR APPROPRIATE. AFTER THE FIRST MEETING, THE COUNCIL SHALL MEET AT
6 LEAST QUARTERLY, OR MORE FREQUENTLY AT THE CALL OF THE CHAIRPERSON
7 OR IF REQUESTED BY 8 OR MORE MEMBERS.

8 (9) A MAJORITY OF THE MEMBERS OF THE COUNCIL CONSTITUTE A
9 QUORUM FOR THE TRANSACTION OF BUSINESS AT A MEETING OF THE COUNCIL.
10 A MAJORITY OF THE MEMBERS PRESENT AND SERVING ARE REQUIRED FOR
11 OFFICIAL ACTION OF THE COUNCIL.

12 (10) THE BUSINESS THAT THE COUNCIL MAY PERFORM MUST BE
13 CONDUCTED AT A PUBLIC MEETING OF THE COUNCIL HELD IN COMPLIANCE
14 WITH THE OPEN MEETINGS ACT, 1976 PA 267, MCL 15.261 TO 15.275.

15 (11) A WRITING PREPARED, OWNED, USED, IN THE POSSESSION OF, OR
16 RETAINED BY THE COUNCIL IN THE PERFORMANCE OF AN OFFICIAL FUNCTION
17 IS SUBJECT TO THE FREEDOM OF INFORMATION ACT, 1976 PA 442, MCL
18 15.231 TO 15.246.

19 (12) MEMBERS OF THE COUNCIL SHALL SERVE WITHOUT COMPENSATION.
20 HOWEVER, MEMBERS OF THE COUNCIL MAY BE REIMBURSED FOR THEIR ACTUAL
21 AND NECESSARY EXPENSES INCURRED IN THE PERFORMANCE OF THEIR
22 OFFICIAL DUTIES AS MEMBERS OF THE COUNCIL.

23 (13) AT OR AFTER THE FIRST MEETING OF THE COUNCIL, THE COUNCIL
24 MAY MAKE RECOMMENDATIONS TO THE GOVERNOR ON THE APPOINTMENT OF
25 ADDITIONAL MEMBERS TO THE COUNCIL THAT THE COUNCIL CONSIDERS
26 NECESSARY OR APPROPRIATE TO CARRY OUT ITS DUTIES.

27 (14) AS USED IN THIS SECTION AND SECTION 5135A:

1 (A) "COUNCIL" MEANS THE RARE DISEASE ADVISORY COUNCIL CREATED
2 IN SUBSECTION (1).

3 (B) "RARE DISEASE" MEANS A DISEASE THAT AFFECTS FEWER THAN
4 200,000 INDIVIDUALS IN THE UNITED STATES.

5 SEC. 5135A. (1) THE COUNCIL MAY DO 1 OR MORE OF THE FOLLOWING:

6 (A) APPLY FOR AND ACCEPT GRANTS AND GIFTS FROM GOVERNMENT AND
7 PRIVATE SOURCES. THE DEPARTMENT SHALL PROVIDE CLERICAL AND
8 ADMINISTRATIVE ASSISTANCE TO THE COUNCIL IN APPLYING FOR GRANTS
9 UNDER THIS SUBDIVISION, AS THE DIRECTOR CONSIDERS NECESSARY OR
10 APPROPRIATE.

11 (B) HOLD PUBLIC HEARINGS AND MAKE INQUIRIES AND RECEIVE
12 COMMENTS FROM THE GENERAL PUBLIC TO ASSIST THE COUNCIL IN
13 DEVELOPING RECOMMENDATIONS UNDER THIS SECTION.

14 (C) CONSULT WITH EXPERTS ON RARE DISEASES TO ASSIST THE
15 COUNCIL IN DEVELOPING RECOMMENDATIONS UNDER THIS SECTION,
16 INCLUDING, BUT NOT LIMITED TO, EXPERTS FROM THE PRIVATE SECTOR,
17 ORGANIZED LABOR GROUPS, GOVERNMENT AGENCIES, AND INSTITUTIONS OF
18 HIGHER EDUCATION.

19 (2) THE COUNCIL SHALL DO ALL OF THE FOLLOWING:

20 (A) RESEARCH AND MAKE RECOMMENDATIONS TO THE LEGISLATURE ON
21 THE QUALITY, COST-EFFECTIVENESS, AND ACCESS TO TREATMENT AND
22 SERVICES PROVIDED TO INDIVIDUALS WITH RARE DISEASES IN THIS STATE,
23 INCLUDING WHICH ISSUES DESCRIBED IN THIS SUBDIVISION SHOULD BE
24 PRIORITIZED IN THIS STATE.

25 (B) IDENTIFY BEST PRACTICES FOR RARE DISEASES FROM OTHER
26 STATES AND AT THE NATIONAL LEVEL THAT COULD IMPROVE THE CARE AND
27 TREATMENT OF ADULTS AND MINORS WITH RARE DISEASES IN THIS STATE.

1 (C) COORDINATE WITH OTHER RARE DISEASE ADVISORY BODIES,
2 COMMUNITY-BASED ORGANIZATIONS, AND OTHER PUBLIC AND PRIVATE
3 ORGANIZATIONS IN PERFORMING ITS DUTIES UNDER THIS SECTION TO ENSURE
4 GREATER COOPERATION BETWEEN THIS STATE, OTHER STATES, AND THE
5 FEDERAL GOVERNMENT REGARDING THE RESEARCH, DIAGNOSIS, AND TREATMENT
6 OF RARE DISEASES, BY DISSEMINATING THE COUNCIL'S RESEARCH,
7 FINDINGS, AND RECOMMENDATIONS WHEN APPROPRIATE.

8 (D) SERVE AS AN ADVISORY BODY ON RARE DISEASES TO THE
9 LEGISLATURE, THE DEPARTMENT, AND THE GOVERNOR.

10 (E) RESEARCH AND MAKE RECOMMENDATIONS TO THE LEGISLATURE ON
11 THE MOST APPROPRIATE METHOD TO COLLECT DATA ON RARE DISEASES.

12 (F) PROVIDE INFORMATION OR ADVICE ON RARE DISEASES TO THE
13 DEPARTMENT OR GOVERNOR, AS THE DIRECTOR OR GOVERNOR CONSIDERS
14 NECESSARY OR APPROPRIATE.

15 (G) BEGINNING DECEMBER 31, 2019, AND BY DECEMBER 31 OF EVERY
16 OTHER YEAR BEGINNING AFTER THE FIRST REPORT IS SUBMITTED TO THE
17 LEGISLATURE UNDER THIS SUBDIVISION, SUBMIT A WRITTEN REPORT TO THE
18 LEGISLATURE ON THE ACTIVITIES, FINDINGS, AND RECOMMENDATIONS OF THE
19 COUNCIL.

20 Enacting section 1. This amendatory act takes effect 90 days
21 after the date it is enacted into law.