

HOUSE BILL NO. 4663

May 23, 2019, Introduced by Reps. Hammoud, Ellison, Mueller, Sowerby, Love, Brixie and Pagan and referred to the Committee on Health Policy.

A bill to create the cystic fibrosis advisory committee; and to prescribe its powers and duties.

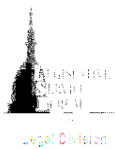
THE PEOPLE OF THE STATE OF MICHIGAN ENACT:

1 Sec. 1. This act shall be known and may be cited as the
2 "cystic fibrosis advisory committee act".

3 Sec. 2. As used in this act, "advisory committee" means the
4 cystic fibrosis advisory committee created in section 3.

5 Sec. 3. (1) The cystic fibrosis advisory committee is created
6 within the department of health and human services.

7 (2) The advisory committee consists of the following members



1 appointed by the governor:

2 (a) Two representatives chosen from lists submitted by the
3 directors of the following foundations:

4 (i) The Michigan chapter of the Cystic Fibrosis Foundation.

5 (ii) The Bonnell Foundation.

6 (iii) The Rock CF Foundation.

7 (iv) Cystic Fibrosis Research, Inc.

8 (v) The Boomer Esiason Foundation.

9 (vi) Emily's Entourage.

10 (vii) The Cystic Fibrosis Lifestyle Foundation.

11 (b) Two representatives of the department of health and human
12 services, from a list submitted by the director of the department
13 of health and human services.

14 (c) Two physicians who are specialists in cystic fibrosis.

15 (d) One cystic fibrosis nurse specialist, 1 social worker, and
16 1 respiratory therapist.

17 (e) Two individuals from a list submitted by the speaker of
18 the house of representatives who either are diagnosed with cystic
19 fibrosis or are relatives of an individual diagnosed with cystic
20 fibrosis.

21 (f) Two individuals who are at least 18 years old who have
22 been diagnosed with cystic fibrosis.

23 (g) Two individuals who are caregivers of an individual less
24 than 18 years old who has been diagnosed with cystic fibrosis.

25 (3) The members first appointed to the advisory committee must
26 be appointed within 90 days after the effective date of this act.

27 (4) Members of the advisory committee shall serve for a term
28 of 1 year or until a successor is appointed, whichever is later.

29 (5) If a vacancy occurs on the advisory committee, the



1 governor shall make an appointment for the unexpired term in the
2 same manner as the original appointment.

3 (6) The governor may remove a member of the advisory committee
4 for incompetence, dereliction of duty, malfeasance, misfeasance, or
5 nonfeasance in office, or any other good cause.

6 (7) The governor shall call the first meeting of the advisory
7 committee. At the first meeting, the advisory committee shall elect
8 from among its members a chairperson and other officers as it
9 considers necessary or appropriate. After the first meeting, the
10 advisory committee shall meet at least quarterly, or more
11 frequently at the call of the chairperson or if requested by a
12 majority of the members.

13 (8) A majority of the members of the advisory committee
14 constitute a quorum for the transaction of business at a meeting of
15 the advisory committee. A majority of the members present and
16 serving are required for official action of the advisory committee.

17 (9) The business that the advisory committee may perform must
18 be conducted at a public meeting of the advisory committee held in
19 compliance with the open meetings act, 1976 PA 267, MCL 15.261 to
20 15.275.

21 (10) A writing prepared, owned, used, in the possession of, or
22 retained by the advisory committee in the performance of an
23 official function is subject to the freedom of information act,
24 1976 PA 442, MCL 15.231 to 15.246.

25 (11) Members of the advisory committee shall serve without
26 compensation. However, members of the advisory committee may be
27 reimbursed for their actual and necessary expenses incurred in the
28 performance of their official duties as members of the advisory
29 committee.



1 (12) The advisory committee shall do all of the following:

2 (a) Review novel therapies and treatments for cystic fibrosis
3 patients to ensure access to quality health care.

4 (b) Review health care and medication access for patients and
5 families affected by cystic fibrosis in this state to eliminate
6 barriers to access.

7 (c) Review funding opportunities for further cystic fibrosis
8 research at accredited hospitals and universities in this state.

9 (d) Study the impact of schooling and employment on cystic
10 fibrosis patients in this state to provide information to school
11 administrators and employers to better serve and allocate necessary
12 resources to cystic fibrosis patients.

13 (e) Study any other cystic fibrosis interests presented to the
14 advisory committee.

15 (f) By December 31 of each year, prepare and submit a report
16 to the house of representatives and the senate on any
17 recommendations for legislation to address any of the issues in
18 subdivisions (a) to (e).

