

# HOUSE BILL No. 5946

May 8, 2018, Introduced by Reps. Hammoud, Ellison, Elder, Gay-Dagnogo and Wittenberg  
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  
8 appointed by the governor:

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

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

2 (ii) The Bonnell Foundation.

3 (iii) The Rock CF Foundation.

4 (iv) Cystic Fibrosis Research, Inc.

5 (v) The Boomer Esiason Foundation.

6 (vi) The Emily's Entourage Foundation.

7 (vii) The Cystic Fibrosis Lifestyle Foundation.

8 (b) Two representatives of the department of health and human  
9 services, from a list submitted by the director of the department  
10 of health and human services.

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

12 (d) One cystic fibrosis nurse specialist, 1 social worker, and  
13 1 respiratory therapist.

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

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

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

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

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

26 (5) If a vacancy occurs on the advisory committee, the  
27 governor shall make an appointment for the unexpired term in the

1 same manner as the original appointment.

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

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

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

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

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

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

1 committee.

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

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

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

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

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

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

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