



2021 SENATE BILL 689

November 11, 2021 - Introduced by Senators JAGLER and COWLES, cosponsored by Representatives DITTRICH, LOUDENBECK, SINICKI, THIESFELDT, SHELTON, MURPHY and DUCHOW. Referred to Committee on Government Operations, Legal Review and Consumer Protection.

1 **AN ACT** *to create* 15.197 (23) and 255.075 of the statutes; **relating to:** rare
2 disease advisory council.

Analysis by the Legislative Reference Bureau

This bill establishes a rare disease advisory council in the Department of Health Services to advise DHS and provide recommendations to both the governor and the legislature regarding issues relating to rare diseases. Under the bill, the council is required to conduct activities to benefit the rare disease community in the state, selecting any combination of four to six options from a list of potential activities that includes, among other things: 1) convening public hearings, making inquiries, and soliciting comments from the general public to assist the council with an ongoing survey of the needs of rare disease patients, caregivers, and health care providers in the state; 2) researching and making recommendations to state agencies and insurers; 3) researching and identifying priorities related to treatment and services provided to rare disease patients and developing policy recommendations that include safeguards against discrimination; 4) evaluating and making recommendations to improve coverage under the Medical Assistance program; 5) publishing a list of publicly available resources; 6) establishing resources to assist with training employees on rare diseases; and 7) researching and identifying best practices in the research, diagnosis, and treatment of rare disease in the state.

The bill requires the council 1) to provide opportunities for the public to obtain updates and provide input into the council's work and 2) to create and maintain a public website that allows for meeting minutes and meeting notices to be posted and public feedback to be submitted.

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For further information see the state fiscal estimate, which will be printed as an appendix to this bill.

The people of the state of Wisconsin, represented in senate and assembly, do enact as follows:

1 **SECTION 1.** 15.197 (23) of the statutes is created to read:

2 15.197 (23) RARE DISEASE ADVISORY COUNCIL. (a) *Creation.* There is created in
3 the department of health services a rare disease advisory council.

4 (b) *Membership.* The council created under this subsection shall consist of all
5 of the following members:

6 1. The chairperson of the senate committee that addresses health issues or
7 another member of that committee designated by the chairperson.

8 2. The ranking minority member of the senate committee that addresses health
9 issues or another member of that committee designated by that ranking minority
10 member.

11 3. The chairperson of the assembly committee that addresses health issues or
12 another member of that committee designated by the chairperson.

13 4. The ranking minority member of the assembly committee that addresses
14 health issues or another member of that committee designated by that ranking
15 minority member.

16 5. The chairperson of the assembly committee that addresses mental health
17 issues or another member of that committee designated by the chairperson.

18 6. The ranking minority member of the assembly committee that addresses
19 mental health issues or another member of that committee designated by that
20 ranking minority member.

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- 1 7. One representative from the University of Wisconsin Hospitals and Clinics
2 Authority.
- 3 8. One representative from the Medical College of Wisconsin.
- 4 9. The program director of the minority health program in the department of
5 health services, or the equivalent position in state government, or his or her
6 designee.
- 7 10. The state Medicaid director or his or her designee.
- 8 11. The commissioner of insurance or his or her designee.
- 9 12. The following members appointed by a majority vote of the members under
10 subds. 1., 3., and 5.:
- 11 a. One geneticist licensed and practicing in Wisconsin.
- 12 b. One registered nurse or advanced practice registered nurse with experience
13 treating rare diseases who is licensed or certified under ch. 441 and practices in this
14 state.
- 15 c. One physician with experience treating rare diseases who is licensed under
16 ch. 448 and practices in this state.
- 17 d. One hospital administrator from a hospital in this state that provides care
18 to persons diagnosed with a rare disease or his or her designee.
- 19 e. Two patients who have a rare disease, including one who is at least 18 years
20 of age, but under 30 years of age, and one who is 30 years of age or older.
- 21 f. Two caregivers of persons with a rare disease, including one who is providing
22 care to a child and one who is providing care to a spouse or parent.
- 23 g. One representative of a rare disease patient organization that operates in
24 this state.

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1 h. One pharmacist with experience dispensing drugs used to treat rare diseases
2 or a representative of the biopharmaceutical industry.

3 (c) *Election of the initial chairperson.* The initial chairperson shall be elected
4 by majority vote of the members under par. (b) 1., 3., 5., and 7. to 11.

5 (d) *Election of the initial vice-chairperson.* The vice-chairperson shall be
6 elected by a majority vote of the members appointed under par. (b) 2., 4., 6., and 7.
7 to 11.

8 (e) *Reports.* 1. No later than one year after the effective date of this act [LRB
9 inserts date], and biennially thereafter, the council shall submit a report to the
10 governor, the secretary of health services, and the commissioner of insurance that
11 does all of the following:

12 a. Describes the activities and progress of the council.

13 b. Provides an update on the status of funding of the council, including a list
14 of grants that were sought, accepted, used, and a description of remaining grant
15 balances.

16 c. Provides recommendations to the governor and the legislature on ways to
17 address the needs of people living with rare diseases in the state.

18 2. Annually, the council shall, under s. 13.172 (3), submit a report to the chief
19 clerk of each house of the legislature, for distribution to the appropriate standing
20 committees that address issues of health and mental health. The report shall
21 provide in-depth information regarding the issues described under subd. 1.a. to c.,
22 and shall include specific recommendations regarding legislation to address the
23 needs of the rare disease community. Upon request by any of these standing
24 committees, the council shall present information regarding the report at a public
25 hearing.

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1 (f) *Terms.* 1. a. The initial chairperson elected under par. (c) shall serve an
2 initial term that runs through June 30, 2025. At the end of his or her initial term,
3 and every 2 years thereafter, members of the council shall, by a majority vote, elect
4 a new chairperson.

5 b. The initial vice chairperson elected under par. (d) shall serve an initial term
6 that runs through June 30, 2025. At the end of his or her initial term, and every 2
7 years thereafter, members of the council shall, by a majority vote, elect a new vice
8 chairperson.

9 2. Except as provided under subd. 1., council members under par. (b) 1., 2., and
10 7. to 11. shall serve 3-year terms.

11 3. Except as provided under subd. 1., council members under par. (b) 3. to 6.
12 shall serve 2-year terms corresponding with the legislative biennium.

13 (g) *Vacancies.* If a vacancy occurs for any member position under par. (b) 12.,
14 the members under par. (b) 1., 3., and 5. shall elect a person to fill the vacancy in a
15 timely manner.

16 (h) *Meetings.* 1. The initial meeting of the council shall occur within 90 days
17 after the effective date of this subsection [LRB inserts date].

18 2. For an initial period determined by the chairperson, the council shall meet
19 at least monthly in person or through use of an online platform. After that initial
20 period, the council will meet on a quarterly basis in person or through use of an online
21 platform on a schedule determined by the chairperson and vice chairperson.

22 **SECTION 2.** 255.075 of the statutes is created to read:

23 **255.075 Rare disease advisory council. (1)** In this section, “council” means
24 the rare disease advisory council under s. 15.197 (23).

SENATE BILL 689**SECTION 2**

1 (2) The council shall advise the department regarding issues relating to rare
2 diseases and shall conduct any combination of 4 to 6 of the following activities to
3 benefit the rare disease community in this state:

4 (a) Convene public hearings, make inquiries, and solicit comments from the
5 general public throughout the state to assist the council with an ongoing survey of
6 the needs of rare disease patients, caregivers, and health care providers in the state.

7 (b) Consult, as needed, with experts on rare diseases both on the council and
8 outside the council to develop policy recommendations to improve patient access to
9 and the quality of rare disease specialists, affordable and comprehensive health care
10 coverage, relevant diagnostics, timely treatment, and other needed services.

11 (c) Research and make recommendations to state agencies and insurers that
12 provide services to persons with a rare disease on the impact of coverage,
13 cost-sharing, tiering, or other utilization management procedures on the provision
14 of treatment and care services.

15 (d) Research and identify priorities related to treatments and services provided
16 to persons with rare diseases in the state, and develop policy recommendations that
17 include safeguards against discrimination for these populations on such issues,
18 including in disaster and public health emergency related planning.

19 (e) Evaluate and make recommendations to improve the Wisconsin newborn
20 screening program.

21 (f) Evaluate and make recommendations to improve coverage of treatment and
22 medications for rare disease patients under the Medical Assistance program.

23 (g) Publish a list of existing, publicly accessible resources on research,
24 diagnosis, treatment, and education relating to rare diseases in Wisconsin on the
25 council's Internet site.

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1 (h) Identify areas of unmet need for research that can inform future studies and
2 reports by the council.

3 (i) Establish resources for academic institutions, state agencies, health care
4 professionals, and other entities to provide training to employees in this state on rare
5 diseases.

6 (j) Identify and distribute educational resources for health care providers to
7 foster recognition and optimize treatment of rare diseases in this state.

8 (k) Research and identify best practices in the research, diagnosis, and
9 treatment of rare disease in this state.

10 (L) Establish best practices and protocols to use during a state of emergency
11 to aid rare disease patients.

12 **(3)** (a) The council shall include in its reports required under s. 15.197 (23) (e)
13 a list of all funding sources.

14 (b) The council has no limit on the amount of money they may accept on behalf
15 of the council.

16 (c) The council may use any funding it receives to carry out its duties under sub.
17 (2).

18 (d) No member of the council may solicit or receive funding on behalf of the
19 council from a lobbyist, as defined under s. 13.62 (11), or from a principal, as defined
20 under s. 13.62 (12).

21 **(4)** The council shall provide opportunities for the public to obtain updates and
22 provide input into the council's work, and shall create and maintain a public Internet
23 site that allows for meeting minutes and notices of upcoming meetings to be posted
24 and public feedback to be submitted.

25 (END)