



130th MAINE LEGISLATURE

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Legislative Document

No. 972

H.P. 718

House of Representatives, March 9, 2021

An Act To Establish the Rare Disease Advisory Council

Reference to the Committee on Health and Human Services suggested and ordered printed.

Robert B. Hunt
ROBERT B. HUNT
Clerk

Presented by Representative CRAVEN of Lewiston.

1 **Be it enacted by the People of the State of Maine as follows:**

2 **Sec. 1. 5 MRSA §12004-I, sub-§48-A** is enacted to read:

3 **48-A.**

4 Human Rare Disease Advisory Council Expenses Only 22 MRSA
5 Services: §1700-B
6 Public Health

7 **Sec. 2. 22 MRSA c. 277** is enacted to read:

8 **CHAPTER 277**

9 **RARE DISEASES**

10 **§1700-B. Rare Disease Advisory Council**

11 **1. Advisory board established.** The Rare Disease Advisory Council, as established
12 in Title 5, section 12004-I, subsection 48-A and referred to in this section as "the council,"
13 advises the commissioner and provides information to the public on issues regarding rare
14 diseases. As used in this section, unless the context otherwise indicates, "rare disease"
15 means a condition or illness that affects fewer than 200,000 persons in the United States.

16 **2. Membership.** The council consists of 14 members appointed by the commissioner
17 as follows:

18 A. Three physicians who practice in the area of cardiology, emergency care,
19 neurology, oncology, orthopedics, pediatrics or primary care and provide care to
20 patients with rare diseases;

21 B. Two registered nurses who provide care to patients with rare diseases;

22 C. Two administrators of hospitals that provide care to patients with rare diseases, or
23 their designees;

24 D. One representative of the department who provides education concerning rare
25 diseases or the management of chronic conditions;

26 E. One representative of the department who is responsible for epidemiology services;

27 F. Two persons over 18 years of age who have suffered from or currently suffer from
28 a rare disease;

29 G. Two parents or guardians who each have a child with a rare disease; and

30 H. One representative of an organization dedicated to providing services to patients
31 suffering from rare diseases.

32 The council may, by affirmative vote of a majority of its members, request that the
33 commissioner appoint to the council additional temporary members who have expertise on
34 issues studied by the council. Such members serve for a period determined by the council.

35 **3. Terms; quorum; meetings.** Members serve for a term of 3 years and elect a chair
36 from among the members. At the end of a term an outgoing member serves until a
37 successor has been appointed. A member may serve multiple terms. The board shall meet

1 at least once every 3 months to conduct business and to elect officers. A quorum is 8
2 members. The affirmative vote of a majority of the members present is necessary to decide
3 any business brought before the board.

4 **4. Staff support.** The department shall provide such administrative support to the
5 council as necessary to carry out the duties of the council.

6 **5. Duties of council.** The council shall:

7 A. Perform a statistical and qualitative examination of the incidence, causes and
8 economic burden of rare diseases in the State;

9 B. Receive and consider reports and input concerning rare diseases from the
10 department and persons whose work relates to rare diseases, including community-
11 based organizations, providers of health care and local and national organizations;

12 C. Increase awareness of the burden caused by rare diseases in the State;

13 D. Identify evidence-based strategies to prevent and control rare diseases;

14 E. Determine the effect of delayed or inappropriate treatment on the quality of life for
15 patients suffering from rare diseases and on the economy of this State;

16 F. Study the effect of early treatment for rare diseases on the quality of life for patients
17 suffering from rare diseases, the provision of services to such patients and
18 reimbursement for such services;

19 G. Increase awareness among providers of health care of the symptoms of and care for
20 patients with rare diseases;

21 H. Evaluate the systems for delivery of treatment for rare diseases in place in the State
22 and develop recommendations to increase the survival rates and quality of life of
23 patients with rare diseases;

24 I. Determine effective methods of collecting data concerning cases of rare diseases in
25 the State to conduct epidemiological studies of rare diseases in the State;

26 J. Establish a comprehensive plan for the management of rare diseases in the State,
27 which must include recommendations for the department, public and private
28 organizations and businesses and for potential sources of funding, and update the
29 comprehensive plan as necessary;

30 K. Develop a registry of rare diseases diagnosed in the State to determine the genetic
31 and environmental factors that contribute to such rare diseases; and

32 L. Compile an annual report, which must include, without limitation, a summary of
33 the activities of the council and any recommendations of the council for legislation or
34 other policies. The council shall:

35 (1) Post the report on a publicly accessible website maintained by the department;
36 and

37 (2) Submit the report to the Governor and the commissioner and to the Executive
38 Director of the Legislative Council for transmittal to the Legislature.

SUMMARY

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This bill creates the Rare Disease Advisory Council to advise the Department of Health and Human Services and the public on issues regarding rare diseases. The bill defines a rare disease as a disease that affects fewer than 200,000 persons in the United States. The council is made up of 14 members, who are health care professionals and others involved with or affected by rare diseases. The council is directed to study a variety of issues regarding rare diseases and their treatment within the State. The council must submit an annual report to the Governor, the Commissioner of Health and Human Services and the Legislature and must post the report on a publicly accessible website.