

STATE OF MAINE

IN THE YEAR OF OUR LORD
TWO THOUSAND TWENTY-TWO

H.P. 718 - L.D. 972

An Act To Establish the Rare Disease Advisory Council

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

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

48-A.

<u>Human</u>	<u>Rare Disease Advisory Council</u>	<u>Expenses Only</u>	<u>22 MRSA</u>
<u>Services;</u>			<u>§1700-B</u>
<u>Public Health</u>			

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

CHAPTER 277

RARE DISEASES

§1700-B. Rare Disease Advisory Council

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

2. Membership. The council consists of 20 members appointed by the commissioner, or the commissioner's designee, as follows:

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

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

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

- D. One representative of the department who provides education concerning rare diseases or the management of chronic conditions;
- E. One representative of the department who is responsible for epidemiology services;
- F. One representative of the department who is responsible for administering the MaineCare program;
- G. The Superintendent of Insurance within the Department of Professional and Financial Regulation, or the superintendent's designee;
- H. One person representing an insurer operating in the State;
- I. One person representing biopharmaceutical companies;
- J. One geneticist practicing in the State;
- K. One person representing an academic research institution in the State;
- L. Two persons over 18 years of age who have had or currently have a rare disease;
- M. Two parents or guardians who each have a child with a rare disease; and
- N. One representative of an organization dedicated to providing services to persons with rare diseases.

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

3. Terms; quorum; meetings. Members serve for a term of 3 years and elect a chair from among the members. At the end of a term an outgoing member serves until a successor has been appointed. A member may serve multiple terms. The board shall meet at least once every 3 months to conduct business and to elect officers. A quorum is 11 members. The affirmative vote of a majority of the members present is necessary to decide any business brought before the board.

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

5. Duties of council. The council shall:

- A. Receive and consider reports and input concerning rare diseases from the department and persons whose work relates to rare diseases, including community-based organizations, providers of health care and local and national organizations;
- B. Increase awareness of the burden caused by rare diseases in the State;
- C. Determine the effect of delayed or inappropriate treatment on the quality of life for persons with rare diseases and on the economy of this State;
- D. Identify and distribute publicly available educational resources to providers of health care in order to foster recognition of symptoms of and treatment for rare diseases among patients of those providers;
- E. Evaluate the systems for delivery of treatment for rare diseases in place in the State and develop recommendations to improve quality of life and to provide services and reimbursement for those services for persons with rare diseases;

F. Convene public hearings and solicit comments from the public related to rare diseases;

G. Establish a comprehensive plan for the management of rare diseases in the State, which must include recommendations for the department, the Department of Professional and Financial Regulation, Bureau of Insurance, public and private organizations and businesses and for potential sources of funding, and update the comprehensive plan as necessary;

H. Distribute and make available publicly accessible resources for the public on research, diagnosis, treatment and education about rare diseases; and

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

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

(2) Submit the report to the Governor, the commissioner and the Superintendent of Insurance within the Department of Professional and Financial Regulation and to the Executive Director of the Legislative Council for transmittal to the Legislature.

6. Authority to report out legislation. The joint standing committee of the Legislature having jurisdiction over health and human services matters may report out legislation related to the report required in subsection 5, paragraph I.

Sec. 3. Staggered terms. Notwithstanding the Maine Revised Statutes, Title 22, section 1700-B, subsection 3, the Commissioner of Health and Human Services, or the commissioner's designee, for the original appointments of members of the Rare Disease Advisory Council as established in Title 5, section 12004-I, subsection 48-A, shall designate the first 6 appointments for a one-year term, the 2nd 6 appointments for a 2-year term and the remaining 7 appointments for a 3-year term.

Sec. 4. Appropriations and allocations. The following appropriations and allocations are made.

**HEALTH AND HUMAN SERVICES, DEPARTMENT OF
Maine Center for Disease Control and Prevention 0143**

Initiative: Provides funding for 0.5 Public Health Educator III position to coordinate all the duties associated with the Rare Disease Advisory Council.

GENERAL FUND	2021-22	2022-23
POSITIONS - LEGISLATIVE COUNT	0.000	0.500
Personal Services	\$0	\$58,166
All Other	\$0	\$6,354
GENERAL FUND TOTAL	\$0	\$64,520