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HEALTH AND HUMAN SERVICES

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**STATE OF MAINE
HOUSE OF REPRESENTATIVES
130TH LEGISLATURE
FIRST SPECIAL SESSION**

COMMITTEE AMENDMENT “ ” to H.P. 718, L.D. 972, “An Act To Establish the Rare Disease Advisory Council”

Amend the bill in section 2 in c. 277 in §1700-B by striking out all of subsection 2 (page 1, lines 16 to 34 in L.D.) and inserting the following:

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;

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- 1 M. Two parents or guardians who each have a child with a rare disease; and
- 2 N. One representative of an organization dedicated to providing services to persons
- 3 with rare diseases.

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

7 Amend the bill in section 2 in c. 277 in §1700-B in subsection 3 in the 4th line (page
8 2, line 1 in L.D.) by striking out the following: "8" and inserting the following: '11'

9 Amend the bill in section 2 in c. 277 in §1700-B by striking out all of subsection 5
10 (page 2, lines 6 to 38 in L.D.) and inserting the following:

11 **'5. Duties of council.** The council shall:

12 A. Receive and consider reports and input concerning rare diseases from the
13 department and persons whose work relates to rare diseases, including community-
14 based organizations, providers of health care and local and national organizations;

15 B. Increase awareness of the burden caused by rare diseases in the State;

16 C. Determine the effect of delayed or inappropriate treatment on the quality of life for
17 persons with rare diseases and on the economy of this State;

18 D. Identify and distribute publicly available educational resources to providers of
19 health care in order to foster recognition of symptoms of and treatment for rare diseases
20 among patients of those providers;

21 E. Evaluate the systems for delivery of treatment for rare diseases in place in the State
22 and develop recommendations to improve quality of life and to provide services and
23 reimbursement for those services for persons with rare diseases;

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

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

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

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

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

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

1 Amend the bill in section 2 in c. 277 in §1700-B by inserting after subsection 5 the
2 following:

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

6 Amend the bill by inserting after section 2 the following:

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

13 **Sec. 4. Appropriations and allocations.** The following appropriations and
14 allocations are made.

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

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

19 GENERAL FUND	2021-22	2022-23
20 POSITIONS - LEGISLATIVE COUNT	0.500	0.500
21 Personal Services	\$58,166	\$60,960
22 All Other	\$6,354	\$6,354
23		
24 GENERAL FUND TOTAL	\$64,520	\$67,314

25 '
26 Amend the bill by relettering or renumbering any nonconsecutive Part letter or section
27 number to read consecutively.

28 **SUMMARY**

29 This amendment, which is the unanimous report of the committee, increases the
30 membership of the Rare Disease Advisory Council and adds staggered terms for the
31 members' initial appointments. It amends the duties of the council and provides the joint
32 standing committee of the Legislature having jurisdiction over health and human services
33 matters authority to report out legislation related to the annual report of the Rare Disease
34 Advisory Council. It also adds an appropriations and allocations section.

35 **FISCAL NOTE REQUIRED**

36 **(See attached)**