

CHAPTER 24
HB 237 - FINAL VERSION

27Feb2019... 0405h

2019 SESSION

19-0199
01/05

HOUSE BILL **237**

AN ACT establishing the New Hampshire rare disease advisory council.

SPONSORS: Rep. Marsh, Carr. 8; Rep. Guthrie, Rock. 13; Rep. Knirk, Carr. 3; Rep. Kotowski, Merr. 24; Rep. Fothergill, Coos 1; Rep. Salloway, Straf. 5; Sen. Bradley, Dist 3; Sen. Rosenwald, Dist 13; Sen. Chandley, Dist 11

COMMITTEE: Health, Human Services and Elderly Affairs

ANALYSIS

This bill establishes the New Hampshire rare disease advisory council to advise the legislature and the department of health and human services on rare diseases in New Hampshire.

Explanation: Matter added to current law appears in ***bold italics***.
 Matter removed from current law appears ~~[in brackets and struckthrough.]~~
 Matter which is either (a) all new or (b) repealed and reenacted appears in regular type.

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STATE OF NEW HAMPSHIRE

In the Year of Our Lord Two Thousand Nineteen

AN ACT establishing the New Hampshire rare disease advisory council.

Be it Enacted by the Senate and House of Representatives in General Court convened:

1 24:1 New Subdivision; New Hampshire Rare Disease Advisory Council. Amend RSA 126-A by
2 inserting after section 77 the following new subdivision:

New Hampshire Rare Disease Advisory Council

4 126-A:78 Definition. For the purposes of this subdivision, a rare disease means a disease
5 affecting 200,000 people or fewer in the United States.

6 126-A:79 New Hampshire Rare Disease Advisory Council Established.

7 I. There is hereby established the New Hampshire rare disease advisory council.

8 II.(a) The advisory council shall consist of the following members:

9 (1) Two members of the house of representatives, appointed by the speaker of the
10 house of representatives.

11 (2) One member of the senate, appointed by the senate president.

12 (3) The commissioner of the department of health and human services, or designee.

13 (4) A physician licensed under RSA 329, appointed by the New Hampshire Medical
14 Society.

15 (5) An APRN, appointed by the New Hampshire Nurse Practitioner Association.

16 (6) A representative of the New Hampshire Hospital Association, appointed by the
17 association.

18 (7) A representative from a health insurer issuing policies in New Hampshire,
19 appointed by the governor.

20 (8) One parent or guardian of a youth with a rare disease, appointed by the
21 governor.

22 (9) Two adult persons living with a rare disease that is distinct from each other's
23 and from that of the person appointed in subparagraph (8), appointed by the governor.

24 (10) A physician or medical researcher specializing in a rare disease who for the first
25 3-year term shall be a medical expert in amyotrophic lateral sclerosis, appointed by the New
26 Hampshire Medical Society.

27 (b) The council may solicit information from any person or entity the advisory council
28 deems relevant to its quest.

29 III. Terms of office shall be for 3 years, except that legislative members shall serve the terms
30 coterminous with their terms of office. No member shall serve more than 2 full consecutive terms.

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1 IV. Members shall elect annually from among their number a chairperson and such other
2 officers as they may determine necessary.

3 V. Legislative members of the advisory council shall receive mileage at the legislative rate.

4 VI. The advisory council shall:

5 (a) Advise the legislature and the department of health and human services on rare
6 diseases in New Hampshire.

7 (b) Coordinate with other states' rare disease advisory bodies, community-based
8 organizations, and other public and private organizations for the purpose of ensuring greater
9 cooperation between state and federal activities encouraging research, diagnosis, and treatment of
10 rare diseases. Federal agencies may include, but are not limited to, the National Institutes of
11 Health, and the United States Food and Drug Administration.

12 (c) Explore existing data on rare diseases in New Hampshire collected by the
13 department of health and human services.

14 (d) Encourage public awareness regarding rare diseases in New Hampshire.

15 VII. The advisory council shall submit an annual report detailing its findings, including
16 recommendations for legislation, commencing on or before December 1, 2020, to the governor, the
17 speaker of the house of representatives, the president of the senate, the commissioner of the
18 department of health and human services, and the oversight committee on health and human
19 services, established in RSA 126-A:13.

24:2 Effective Date. This act shall take effect 60 days after its passage.

Approved: May 15, 2019

Effective Date: July 14, 2019