

2025 -- S 0474

LC002079

STATE OF RHODE ISLAND

IN GENERAL ASSEMBLY

JANUARY SESSION, A.D. 2025

A N A C T

RELATING TO HEALTH AND SAFETY -- RARE DISEASE ADVISORY COUNCIL

Introduced By: Senators Lawson, Lauria, Tikoian, Murray, Sosnowski, Britto, DiMario, Valverde, and Ujifusa

Date Introduced: February 26, 2025

Referred To: Senate Health & Human Services

It is enacted by the General Assembly as follows:

1 SECTION 1. Legislative findings.

2 The general assembly hereby finds and declares:

3 (1) A rare disease, sometimes called an orphan disease, is defined as a disease that affects
4 fewer than two hundred thousand (200,000) people in the United States.

5 (2) There are more than ten thousand (10,000) known rare diseases affecting approximately
6 25 million to 30 million Americans, more than half of which are children.

7 (3) More than ninety percent (90%) of rare diseases do not have a Food and Drug
8 Administration (FDA) approved treatment.

9 (4) While the exact cause for many rare diseases remains unknown, many rare diseases are
10 genetic in origin and can be linked to mutations in a single gene or in multiple genes, which can be
11 passed down from generation to generation.

12 (5) People with rare diseases face many challenges, including delays in obtaining an
13 accurate diagnosis, finding a healthcare provider with expertise in their condition, and a lack of
14 affordable access to therapies and medication used to treat rare diseases.

15 (6) A state-based advisory council composed of qualified professionals and persons living
16 with rare diseases and their caregivers could educate medical professionals, government agencies,
17 legislators, and the public about rare diseases as an important public health issue and encourage
18 research into the development of new ways to diagnose and treat rare diseases.

19 SECTION 2. Title 23 of the General Laws entitled "HEALTH AND SAFETY" is hereby

1 amended by adding thereto the following chapter:

2 CHAPTER 87.1

3 RARE DISEASE ADVISORY COUNCIL

4 **23-87.1-1. Short title.**

5 This chapter shall be known and may be cited as the "Rare Disease Advisory Council."

6 **23-87.1-2. Establishment.**

7 (a) There is established in the department of health a council to be called the "rare disease
8 advisory council".

9 (b) The purpose of the council is to provide guidance and recommendations to educate the
10 public, legislature, as well as other government agencies, on the needs of individuals with rare
11 diseases living in Rhode Island.

12 (c) The council shall conduct the following activities to benefit those impacted by rare
13 diseases in Rhode Island. The duties of the council shall include:

14 (1) Convene public hearings, make inquiries, and solicit comments from the general public
15 in Rhode Island to assist the council with a first-year landscape or survey of the needs of rare
16 disease patients, caregivers, and providers in the state.

17 (2) Provide testimony and comments on legislation and regulations affecting Rhode
18 Island's rare disease community and recommend solutions to state agencies and insurers on the
19 impact of orphan drug pricing, prior authorization, cost-sharing, and other treatment barriers.

20 (3) Establish best practices and protocols to include in-state planning related to natural
21 disasters, public health emergencies or other emergency declarations to enable continuity of care
22 for rare disease patients and ensure safeguards against discrimination for rare disease patients are
23 in place.

24 (4) Research and identify best practices to reduce health disparities and achieve health
25 equity in the research, diagnosis and treatment of rare diseases in Rhode Island, including strategies
26 to improve continuity of care during transitions from child/youth to adult services.

27 (5) Identify, develop, and distribute educational resources for healthcare providers to foster
28 recognition, optimize treatment, and improve care for rare disease patients.

29 (6) Maintain a publicly accessible list of resources on research, diagnosis, treatment, and
30 education related to rare diseases in Rhode Island on the council's website.

31 **23-87.1-3. Membership of council.**

32 (a) The council's appointment process shall be conducted in a transparent manner to
33 provide interested individuals an opportunity to apply for membership on the council. All members
34 of the council shall be full-time residents of Rhode Island and membership shall include a diverse

- 1 set of stakeholders.
- 2 (b) The council shall include representatives from the following groups with individuals
3 potentially fulfilling multiple roles if they meet qualifications for more than one category:
- 4 (1) One representative from academic research institutions in the state that receives any
5 grant funding for rare disease research appointed by the governor;
- 6 (2) One representative from the department of health's office of minority health;
- 7 (3) One representative from the Rhode Island Medicaid agency;
- 8 (4) One representative from the office of the health insurance commissioner;
- 9 (5) One registered nurse or advanced practice registered nurse licensed and practicing in
10 Rhode Island with experience treating rare diseases appointed by the governor;
- 11 (6) One physician practicing in Rhode Island with experience treating rare diseases
12 appointed by the governor;
- 13 (7) One hospital administrator, or designee, from a hospital in Rhode Island that provides
14 care to persons diagnosed with a rare disease appointed by the governor;
- 15 (8) At least two (2) patients who have a rare disease; one to be appointed by the speaker of
16 the house of representatives and one to be appointed by the president of the senate;
- 17 (9) At least one caregiver of a person with a rare disease appointed by the speaker of the
18 house of representatives;
- 19 (10) One representative of a rare disease patient organization that operates in Rhode Island
20 appointed by the president of the senate;
- 21 (11) A pharmacist with experience dispensing drugs used to treat rare diseases appointed
22 by the president of the senate;
- 23 (12) A representative of the biopharma industry appointed by the governor;
- 24 (13) A representative of a health plan company appointed by the speaker of the house of
25 representatives;
- 26 (14) A member of the scientific community who is engaged in rare disease research
27 including, but not limited to, a medical researcher with experience conducting research on rare
28 diseases appointed by the president of the senate; and
- 29 (15) A licensed mental health provider practicing in Rhode Island with experience
30 supporting individuals diagnosed with rare diseases and their families appointed by the governor.

31 **23-87.1-4. Terms and vacancies for council members.**

- 32 (a) Term of members. Council members shall serve no longer than three (3) years, except
33 that, to facilitate a staggered rotation of members to retain continuity and knowledge transfer,
34 during the initial five (5) years after the establishment of the council, members may serve up to a

1 four (4) year term. The council shall develop its own bylaws to address the reappointment of its
2 members.

3 (1) Members may continue to serve until their successor is duly appointed.

4 (b) The chair of the council shall be determined by a majority vote of the members of the
5 council during its inaugural meeting. The chair shall not hold any positions within Rhode Island
6 state government.

7 (1) At the end of the chair's initial three (3) year term, by a majority vote, a new chair shall
8 be elected.

9 (2) The council shall develop its own internal bylaws to address the possibility of a chair
10 being elected more than once.

11 (c) If a vacancy occurs, the vacancy shall be filled in a like manner as required pursuant to
12 this section.

13 **23-87.1-5. Reporting requirements.**

14 (a) The council shall submit a report to the governor, the speaker of the house, the president
15 of the senate, and the chairs of the house and senate health and finance committees, including the
16 joint committee on healthcare oversight established pursuant to § 40-8.4-14, and the advisory
17 commission on health care established pursuant to § 40-8.4-15, within one year of the effective
18 date of this chapter and annually thereafter. Prior to submission, a draft of the annual report shall
19 be made available for public comment and discussed at an open public meeting.

20 (b) Annual reports shall:

21 (1) Describe the activities and progress of the council under this section;

22 (2) Include an assessment of the council's progress in meeting its goals, including
23 measurable outcomes, identified barriers, and recommendations for improvement;

24 (3) Provide an update on the status of funding of the council; and

25 (4) Provide recommendations to the governor and general assembly on ways to address the
26 needs of people living with rare diseases in the state.

27 **23-87.1-6. Funding for council.**

28 (a) The council members may solicit funds on behalf of the council.

29 (b) The council shall establish a restricted receipt account and all funds designated or raised
30 by or for the advisory council shall be placed in the restricted receipt account to support the
31 activities of the council necessary to implement the provisions of this chapter.

32 (c) The council shall report funding sources in the annual reports outlined in § 23-87.1-5.

33 (d) The council is authorized to accept state grants and appropriations, and provide monies
34 for its operational purposes.

1 **23-87.1-7. Meeting requirements.**

2 (a) Frequency.

3 (1) The initial meeting of the council shall occur within the first ninety (90) days after the
4 effective date of this chapter.

5 (2) During the first twelve (12) months after the initial meeting, the council shall meet each
6 month. Meetings may be held in person, online, or combination of both.

7 (3) Thereafter, the council shall meet once per quarter in person or via online meeting
8 platform as determined by the chair.

9 (b) Notice. The council shall, in compliance with chapter 46 of title 42 ("open meetings"):

10 (1) Provide opportunities for the public to hear updates and provide input into their work;
11 and

12 (2) Create and maintain a public website where meeting minutes, notices of upcoming
13 meetings, and public comments can be submitted.

14 (c) The department of health shall maintain a publicly accessible webpage on its official
15 website dedicated to the rare disease advisory council. The webpage shall include information
16 about the council meetings, including schedules, agendas, minutes, and details on public
17 participation.

18 SECTION 3. This act shall take effect upon passage.

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EXPLANATION
BY THE LEGISLATIVE COUNCIL
OF
A N A C T
RELATING TO HEALTH AND SAFETY -- RARE DISEASE ADVISORY COUNCIL

- 1 This act would establish a rare disease advisory council within the department of health to
- 2 provide guidance and recommendations to educate healthcare providers and the citizens of the state.
- 3 This act would take effect upon passage.

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