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## MEMORANDUM

**TO:** Representative Brian Kennedy

**FROM:** The National Organization for Rare Disorders (NORD) and the RI RDAC Coalition

**DATE:** February 3, 2025

**SUBJECT:** Recommended Amendments to 2025 Rhode Island Rare Disease Advisory Council (RDAC) Bill H5023

Thank you for your continued support of the Rhode Island rare disease community and for your work championing legislative efforts to create a Rhode Island RDAC in the 2024 legislative session. This memorandum outlines proposed amendments to H5023 (2025), reflecting enhancements to improve the council's functionality and long-term impact. These changes were developed in collaboration with a diverse coalition of Rhode Island stakeholders including patients, caregivers, providers, researchers and industry representatives.

### Summary of Proposed Amendments to H5023:

#### 1. Definition of Rare Disease

- **H5023:** States there are more than 7,000 known rare diseases impacting 25-30M Americans.
- **Amendments:** Updates the estimated number of rare diseases from 7,000 to 10,000 impacting 30M Americans to reflect latest data from the [National Center for Advancing Translational Sciences \(NCATS\)](#).

#### 2. Council Set Up

- **H5023:** Establishes the Office of the Rare Disease Advisory Council within the Rhode Island Department of Health (RIDOH).
- **Amendments:** Maintains housing within RIDOH but makes it a council instead of a dedicated office.

#### 3. Council Duties

- **H5023:** Defined 12 duties, focused on policy recommendations, public hearings, and testimony on legislation.
- **Amendments:** Consolidated duties into five (5) key areas: policy recommendations and public hearings, addressing health disparities and continuity of care, distributing education resources to healthcare providers, establishing protocols for emergencies, and maintaining a public resource list on the council's website.

#### 4. Council Membership Structure

- **H5023:** The Governor appoints all council members.
- **Amendments:** The Governor, Speaker of the House, and President of the Senate each appoint specific members, ensuring balanced representation. New language allows

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individuals to fulfill multiple roles if qualified and ensures total membership remains an odd number, with the Governor authorized to add members to meet this requirement.

- **Amendments:** Adds a seat for a licensed mental health professional such as a psychologist, psychiatrist, or clinical social worker.

#### 5. Meeting Requirements

- **H5023:** Required monthly meetings in the first year and quarterly thereafter, with in-person or online options.
- **Amendments:** Retains the meeting frequency but explicitly allows hybrid formats to maximize public participation and enhanced transparency via a public dedicated website for meeting notices, agendas, and minutes.

#### 6. Reporting Requirements

- **H5023:** Required annual reports to the Governor and relevant committees with health jurisdiction with public comment opportunities.
- **Amendments:** Adds the Joint Committee on Health Care Oversight and the Advisory Commission on Health Care as recipients. Reports must include an assessment of progress with measurable outcomes and identified barriers.

#### 7. Funding Provisions

- **H5023:** Allowed the council members to solicit funds and set up a method to securely hold and distribute such funds.
- **Amendments:** Additionally, authorizes the council to accept state grants, appropriations and provide money for its operational purposes.

#### 8. Chairperson Selection and Term Limits

- **H5023:** The Governor appointed the chair for an initial 3-year term.
- **Amendments:** The Chair is elected by majority vote at the inaugural meeting.

#### Conclusion

These amendments reflect the vision of a dedicated grassroots group of rare disease advocates living, studying, and working in Rhode Island to establish a RDAC that would be flexible, resilient, and capable of adapting to the evolving healthcare landscape in Rhode Island.

We look forward to working with you to improve the lives of individuals impacted by rare diseases and their families in Rhode Island.

Respectfully,



Carolyn G. Sheridan, MPH, State Policy Manager  
National Organization for Rare Disorders®



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