NORD®
National Organization
for Rare Disorders

Alone we are rare. Together we are strong.®

February 3, 2025

The Honorable Brain Kennedy
Speaker Pro Tempore
Rhode Island House of Representatives
82 Smith Street
Providence, RI 02903

RE: NORD Support with Recommendations for H5023 – Establishing the Rhode Island Rare Disease Advisory Council

Dear Representative Kennedy,

On behalf of the National Organization for Rare Disorders (NORD), I write to express our strong support for the vision behind H5023, which establishes a Rare Disease Advisory Council (RDAC) in Rhode Island. We appreciate your leadership in advancing policies that recognize and address the challenges faced by the 1 in 10 Americans living with rare diseases.

NORD supports the creation of a state-based RDAC housed within the Rhode Island Department of Health (RIDOH) to provide critical policy recommendations, amplify the voices of patients and caregivers, and inform legislative efforts affecting the rare disease community. The establishment of this council represents a significant step toward improving health care access and advancing research for individuals with rare diseases.

While we fully support the underlying intent of H5023, we recommend the following refinements to ensure the council reflects the vision and needs of advocates living, working, and studying in Rhode Island:

1. **Clarify Council Structure** – Maintain the RDAC within RIDOH as a council rather than an office, ensuring flexibility in operations.

2. **Refine Council Duties** – Streamline responsibilities into five key focus areas: policy recommendations, addressing health disparities, provider education, emergency preparedness, and public resource accessibility.

3. **Enhance Membership Appointments** – Balance representation by expanding appointing authority beyond the Governor to include the Speaker of the House and President of the Senate while ensuring an odd-numbered membership for quorum purposes.

4. **Strengthen Public Engagement** – Expand public accessibility and transparency by requiring a dedicated RDAC website to house meeting notices, minutes, and reports. Additionally, formalize hybrid meeting options to encourage broad participation.

5. **Improve Reporting & Oversight** – Require annual reports to include measurable outcomes and barriers and ensure submission to the Joint Committee on Health Care Oversight and the Advisory Commission on Health Care, in addition to the Governor and Legislature.

6. **Expand Funding Mechanisms** – Authorize the RDAC to accept state grants and appropriations to support operations.

7. **Adjust Leadership Selection** – Ensure the RDAC Chair is elected by council members, rather than appointed by the Governor, to reinforce independent governance.

By incorporating these amendments, H5023 will better serve Rhode Island's rare disease community while fostering long-term sustainability and adaptability in the evolving healthcare landscape. We are grateful for your continued support and look forward to working together to advance policies that enhance the quality of life for those affected by rare diseases.

Sincerely,

C Sheridan

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

CC:
Senator Valarie Lawson, Majority Leader, Rhode Island State Senate
Steven Sepe, Committee Clerk, Rhode Island House of Representatives Committee on Health and Human Services
Leah Barber, Director of Grassroots Advocacy, National Organization of Rare Disorders (NORD)