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National Organization for Rare Disorders

NORD TESTIMONY – RHODE ISLAND S474 – HHS

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Opening:

Good afternoon, Chair Murray, members of the committee, and dedicated staff. My name is Carolyn Sheridan, and I am here on behalf of the National Organization for Rare Disorders (NORD) to express strong support for Senate Bill S.474, which would establish a Rhode Island Rare Disease Advisory Council (RDAC).

The National Organization for Rare Disorders (NORD) is a federation of non-profits and health organizations dedicated to improving the health and wellbeing of people living with rare diseases. We have over 350 member organizations which represent patients and caregivers living with any of the over 10,000 known rare diseases.

I want to begin by thanking Senator Valarie Lawson for championing this critical legislation and for so many of you signing on as co-sponsors. I appreciate the opportunity to speak to you all today.

Why Rhode Island Needs a RDAC:

One in ten Americans. Thousands of Rhode Islanders. Living with diseases so rare, many doctors will never see a case in their entire careers. Despite their unique conditions, rare disease patients often face similar systemic challenges: delayed diagnoses, lack of treatment options, and difficulty accessing knowledgeable providers.

Rhode Island remains one of the few states in the Northeast without a Rare Disease Advisory Council (RDAC), while neighboring states have recognized the need for a dedicated body to address rare disease challenges.

Establishing an RDAC would align Rhode Island with the regional and national movement to ensure rare disease patients, caregivers, providers, and experts have a formal role in shaping state health policy.

Key Strengths of S474:

NORD strongly supports S.474 and appreciates the leadership of Senator Lawson in advancing this bill which reflects the input, expertise and lived experience of a broad and committed coalition of advocates living and working in Rhode Island.

The people who shaped this proposal—patients and caregivers, future physicians, industry professionals, and advocates—know firsthand what Rhode Island's rare disease community needs. Their voices have been at the center of this process, and their insights will help set the RDAC up for lasting success.

I am please to note that amendments have been submitted in the House to align H5023 with S474, and the House sponsor is actively engaged and open to these alignments.

On the bill, I'd like to highlight a few of the legislation's core strengths:

- First, the bill effectively focuses the RDAC on five core responsibilities:
    1. Policy Recommendations & Public Hearings – Ensuring the RDAC can analyze state policies and provide expert recommendations.
    2. Health Disparities & Continuity of Care – Addressing the challenges that rare disease patients face when transitioning between pediatric and adult healthcare services.
    3. Provider Education & Training – Equipping Rhode Island's medical community with the tools to recognize and diagnose rare diseases.
    4. Emergency Preparedness & Public Health Planning – Ensuring continuity of care for rare disease patients during public health emergencies or natural disasters.
    5. Publicly Accessible Resources – Providing a dedicated online space where patients, families, and providers can access rare disease-related information.

- Second, authorizing the RDAC to receive state funding and grants to support its operations.
    - RIDOH estimates that operating the council will require 0.5FTE - cost $60,000 to $80,000 annually.
    - Many RDACs in other states are able to secure grants and state appropriations to sustain their work.
    - This provision would ensure that Rhode Island's RDAC is fully supported in carrying out its mission.

Closing Statement:

S474 is an opportunity for Rhode Island to join the growing list of states taking **proactive steps to support the rare disease community**. (30 states have created one of these councils and this year 10 states have legislation active to establish one.)

I appreciate your time and consideration, and I welcome any questions the Committee may have.