NORD®
National Organization
for Rare Disorders

Alone we are rare. Together we are strong.®

April 30, 2024

The Honorable Joshua Miller
Chair
Senate Committee on Health & Human Services
State House
82 Smith Street
Providence, RI 02903

RE: NORD Supports H7363 (Kennedy)/S2390 (Lawson) – Establishes a Rare Disease Advisory Council in the State of Rhode Island

Dear Chair Miller and Members of the Senate Committee on Health and Human Services,

The National Organization for Rare Disorders (NORD), writes to express our enthusiastic support for H7363 (Kennedy)/S2390 (Lawson), which would establish a Rare Disease Advisory Council (RDAC) in the state, giving a voice to the estimated 1-in-10 individuals living with a rare disease in Rhode Island (RI).

NORD is a federation of non-profits and health organizations dedicated to improving the health and wellbeing of people living with rare diseases by driving advances in policy, research, and care. We have over 330 member organizations, which represent patients and caregivers living with one of the over 10,000 known rare diseases. For forty years, NORD has been at the forefront of advocacy for policies and programs such as the creation of state RDACs.

As defined by the Orphan Drug Act, a rare disease is any disease or condition that affects less than 200,000 people in the United States. It is estimated that more than 30 million Americans are living with a rare disease. Through Project RDAC, NORD is working to establish an effective RDAC in every state in the country to help address the complex needs of the rare community at the state level. NORD is eager to welcome Rhode Island to the community of 28 states that have given their rare disease patients a stronger voice in state government by creating a RDAC. Those states include Rhode Island's neighbors, Massachusetts and Connecticut, as well as Alabama, Colorado, Connecticut, Delaware, Florida, Georgia, Illinois, Indiana, Kentucky, Louisiana, Maine, Maryland, Minnesota, Mississippi, Missouri, Nevada, New Jersey, New Hampshire, New York, North Carolina, Ohio, Pennsylvania, South Carolina, Tennessee, Utah, Virginia, and West Virginia.

H7363/S2390 creates the Office of a Rare Disease Advisory Council within Rhode Island's Department of Health to provide guidance and recommendations to educate the public, General Assembly, as well as other government agencies on the needs of individuals with rare diseases living in Rhode Island. Rhode Island's RDAC would be made up of at least fifteen appointed members, representing a diverse set of stakeholders in the rare disease community, including individuals living with a rare disease, a caregiver of a person with a rare disease, a representative of a rare disease patient organization, a physician practicing in RI with experience treating rare disease patients, a nurse practicing in the state with rare disease treatment experience, representatives from health insurance and biopharmaceutical companies, a member of the scientific community engaged in rare disease research, and a representative of an academic research institute that receives grant funding for rare disease research. There are also positions for a representative of the RI Health Department's Office of Minority Health, the Rhode Island Medicaid Agency, and the Department of Business Regulation Insurance Division.

The Council must meet monthly in the first year of enactment and quarterly thereafter as they work to address eleven duties. To help fulfill its duties, the RDAC will be tasked with convening public hearings, making inquiries, and soliciting comments from the public to assist the Council with a population survey of the needs of the rare community in RI. The design and dissemination of these population surveys are a cornerstone of the other Councils across the country and provide much-needed information on the experiences of rare patients in the State. The legislation also requires the Council to provide testimony and comments on pending relevant legislation and rules and advise on policy matters related to patient access and affordability, diagnostic and treatment service accessibility, and drug affordability and utilization management strategies by health plans. Existing policies and programs such as the State's Newborn Screening Program and Medicaid program will also have the expertise of the RDAC availed to them as the Council fulfills duties to evaluate and issue recommendations for improvements to those programs. Through the creation of a webpage on the Department of Health's website, the Council will also identify and distribute educational resources for health care providers to increase awareness of the treatment of rare diseases and work to reduce health disparities and achieve health equity in the research, diagnosis, and treatment of rare diseases in Rhode Island.

With diverse membership and broad community support within and outside Rhode Island, a Rhode Island RDAC will serve as a valuable resource as our health care system evolves. A strong RDAC can help relieve burdens on the state by expeditiously delivering direct feedback, solutions, and resources to Rhode Island government decision makers with one community voice. Without an RDAC, RI laws and regulations that affect the rare community may be developed without the consultation of rare disease stakeholders, leaving this vulnerable population at greater risk for poor health and economic outcomes.

NORD thanks Senator Lawson and Representative Kennedy for their introduction and sponsorship of the bill in their respective Chambers. Additionally, we thank you as Chair for giving the bill a place on the agenda and urge asks for the Committee's favorable report. We hope you consider NORD a resource for you as this bill moves through the legislative process and look forward to working with you and your staff to improve the lives of rare disease patients and their families living in Rhode Island. If you have any questions or need further assistance, please contact Carolyn Sheridan at csheridan@rarediseases.org .

Sincerely,

C Sheridan

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

CC:
Robin Dionne, Committee Clerk, Rhode Island Senate Committee on Health and Human Services