



February 8, 2024

The Honorable Susan R. Donovan, Chair
House Committee on Health and Human Services
Rhode Island House of Representatives
82 Smith St.
Providence, RI 02093

RE: Support for H. 7363 – Establishes a Rare Disease Advisory Council in the State of Rhode Island

Dear Representative Stone,

The National Organization for Rare Disorders (NORD) writes today in support of H. 7363, legislation that would establish a Rare Disease Advisory Council (RDAC) in Rhode Island.

The National Organization for Rare Disorders 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 330+ member organizations which represent patients and caregivers living with any of the over 10,000 known rare diseases. For forty years, we have been at the forefront of advocacy for policies and programs such as the creation of state Rare Disease Advisory Councils that help to give a voice to the estimated 1-in-10 individuals living with a rare disease.

As defined by the Orphan Drug Act¹, 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. Rare disease patients face many unique challenges every day, from obtaining an accurate diagnosis and accessing medical specialists with knowledge of their condition, to battling for fair insurance coverage of their treatment and care. However, due to small patient populations and the variety of rare diseases, it can be difficult for state government officials to have an in-depth understanding of the rare disease community's needs. This lack of awareness often contributes to the obstacles faced by rare disease patients and their loved ones.

This legislation creates a Rare Disease Advisory Council within Rhode Island's Department of Health to provide guidance and recommendations to the public, General Assembly, and other governmental bodies regarding the needs of individuals living with a rare disease in Rhode Island. Rhode Island's RDAC would be made up of fifteen appointed members including individuals living with a rare disease, caregivers to those with rare disease, medical and scientific professionals with experience treating and researching rare disease, and representatives from the health plan industry, biotech industry, and patient organizations.

¹ [United States Food & Drug Administration, Rare Diseases at FDA](#)

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The Council must meet monthly in the first year of enactment and at the call of the chair thereafter as they work to address twelve duties outlined within the legislation. 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 Rhode Island. 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.

NORD is eager to welcome Rhode Island to the community of 27 states that have given their rare disease patients a stronger voice in state government by creating a Rare Disease Advisory Council (RDAC). Those states are: Alabama, Colorado, Connecticut, Delaware, Florida, Georgia, Illinois, Indiana, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Minnesota, Missouri, Nevada, New Hampshire, New Jersey, New York, North Carolina, Ohio, Pennsylvania, South Carolina, Tennessee, Utah, Virginia, and West Virginia.

NORD, on behalf of the estimated one in ten Rhode Islanders living with a rare disease urge your support for H.7363 when it's heard in your Committee. 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 me at csheridan@rarediseases.org.

Sincerely,



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

