



Alone we are rare. Together we are strong.®

January 16, 2025

Committee on Revenue and Economic Development
Nevada State Senate
401 S. Carson Street
Carson City, NV 89701

Dear Members of the Senate Committee on Revenue and Economic Development,

On behalf of the 1-in-10 individuals in Nevada living with one of the more than 10,000 known rare diseases, including thousands of children, the National Organization for Rare Disorders (NORD) urges you to reconsider including Nevada's Rare Disease Advisory Council (RDAC) in the proposal outlined in SB 78.

While NORD understands that the intent of this legislation is to streamline government functions and consolidate its advisory bodies, it is critical to recognize the unique role that the RDAC plays in serving Nevada's rare disease community.

Rare disease patients across the country often face unique challenges, from obtaining an accurate diagnosis and accessing medical specialists with knowledge of their condition, to battling for insurance coverage of their treatment and care. RDACs address these issues by providing a forum for stakeholders who understand and advocate for the needs of rare disease patients, and allows them to make recommendations to improve public policy for the rare disease community. The Nevada RDAC is an exemplar of this work.

The Nevada RDAC has continually raised awareness of rare disease issues among policymakers, health care providers, and the general public, helping to shape policies that improve health care access and equity for the rare disease community.

Eliminating the RDAC and transferring its responsibilities to the Wellness and Prevention Advisory Council, as outlined in SB 78, would create significant setbacks to the rare disease community in Nevada. While we appreciate the goal of efficiency, this change would create the loss of many of the rare disease experts that currently serve on the RDAC. These experts, who are rare disease patients and caregivers, physicians and nurses who treat rare disease, and others with specialized knowledge, are integral to the goal of the RDAC – to provide knowledge and expertise specific to the rare disease community.

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NORD respectfully urges you to remove the Nevada Rare Disease Advisory Council from the provisions of SB 78 and allow the RDAC to continue operating independently. The voices of the rare disease community must not be lost in broader discussions, as these individuals and families rely on the Council's leadership and advocacy.

I would welcome the opportunity to discuss the critical work of the Nevada RDAC at your convenience and can be reached at LViscarra@rarediseases.org. Thank you for your attention to this matter, and I look forward to working with you to ensure that the rare disease community in Nevada continues to receive the support it deserves.

Sincerely,



Lindsey Viscarra
State Policy Manager
National Organization for Rare Disorders

CC: Leah Barber, Director of Grassroots Advocacy, NORD