



Alone we are rare. Together we are strong.®

February 7, 2024

The Honorable Steve Montenegro, Chair
The Honorable Barbara Parker, Vice-Chair
Arizona House Committee on Health and Human Services
Arizona State House of Representatives
Arizona State Capitol Complex
1700 W. Washington St
Phoenix, AZ 85007

Dear Chair Montenegro, Vice-Chair Parker, and Members of the House Committee on Health and Human Services,

On behalf of the 1-in-10 individuals in Arizona living with one of the more than 10,000 known rare diseases, the National Organization for Rare Disorders (NORD) urges your support for House Bill 2758 (Hernandez), which would establish a Rare Disease Advisory Council (RDAC) in Arizona.

Rare disease patients in Arizona face 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. The Arizona RDAC would help address these issues by providing a forum for stakeholders across the state knowledgeable about the needs of rare disease patients to make recommendations on how to improve public policy that impacts our community.

The RDAC will be a valuable advisory body to elected officials and other state leaders on research, education, diagnosis, care and treatment for those with rare diseases. It will also be tasked with providing a report to the Governor and the Legislature, highlighting the Council's findings, activities, and recommendations for addressing the needs of rare disease patients in the state. The RDAC would help relieve some of the burden on the state by expeditiously delivering direct feedback, solutions, and resources to Arizona government decisionmakers with one community voice.

In creating this council, Arizona would join twenty-seven other states (Alabama, Colorado, Connecticut, Delaware, Florida, Georgia, Illinois, Indiana, Kentucky, Louisiana, Maine, Maryland,

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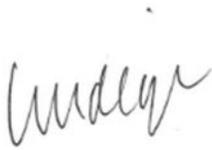
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Massachusetts, Minnesota, Missouri, Nevada, New Hampshire, New Jersey, New York, North Carolina, Ohio, Pennsylvania, South Carolina, Tennessee, Utah, Virginia, and West Virginia) that have already enacted similar legislation in support of their rare disease community and proven that an RDAC can be an invaluable resource.

NORD urges your support for this important legislation, and asks you to set HB2758 for a hearing as soon as possible. NORD and the rare disease community appreciate your commitment to providing a voice for those living with rare diseases and their caregivers in Arizona.

Sincerely,



Lindsey Viscarra
State Policy Manager, Western Region
National Organization for Rare Disorders



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