NORD®
National Organization
for Rare Disorders

Alone we are rare. Together we are strong.®

March 7, 2025

The Honorable Carine Werner
Chair, Committee on Health & Human Services
Arizona State Senate
1700 W. Washington St.
Phoenix, AZ 87007

Re: Support for House Bill 2380

Dear Chair Werner and Members of the Committee on Health & Human Services,

On behalf of the estimated 1-in-10 Americans living with one of the more than 10,000 known rare diseases, the National Organization for Rare Disorders (NORD) urges your support of House Bill 2380, legislation to establish a Rare Disease Advisory Council (RDAC), when it comes before your Committee for consideration on March 12.

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 knowledgeable about the needs of rare disease patients to make recommendations on how to improve public policy that impacts the community.

The RDAC will be a valuable advisory body to elected officials and other state leaders on rare disease research, education, diagnosis, care and treatment. It will be tasked with conducting a first-year landscape survey of rare disease needs in Arizona, providing testimony and recommendations on pending legislation impacting the rare disease community, developing policy recommendations that would improve rare disease patient access to quality care, making recommendations to state agencies and insurers, and distributing educational resources to health care providers regarding rare disease. The RDAC would also help relieve some of the burden on the state by expeditiously delivering direct feedback, solutions, and resources to Arizona policy decisionmakers with one community voice.

In creating this council, Arizona would join thirty other states (Alabama, California, Colorado, Connecticut, Delaware, Florida, Georgia, Illinois, Indiana, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Michigan, Minnesota, Mississippi, Missouri, Nevada, New Hampshire, New Jersey, New York, North Carolina, Ohio, Pennsylvania, South Carolina, Tennessee, Utah, Virginia, and West Virginia) that have established an RDAC in support of their rare disease community and proven that an RDAC can be an invaluable resource.

Chair Werner, NORD thanks you for scheduling a hearing on House Bill 2380 in your Committee and urge its swift advancement. We appreciate your support for this important legislation that will help give a voice to those living with a rare disease in Arizona. Please feel free to contact me at lviscarra@rarediseases.org for any questions or assistance.

Sincerely,

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

CC: Leah Barber, Director of Grassroots Advocacy, NORD