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January 28, 2025

The Honorable Selina Bliss
Chair
Arizona House Committee on Health & Human Services
1700 W. Washington St.
Phoenix, AZ 85007

Re: Support for House Bill 2380

Dear Chair Bliss and Members of the Committee on Health & Human Services:

On behalf of the undersigned organizations representing individuals with rare diseases in Arizona, we urge your support of House Bill 2380 (Hernandez, A). HB 2380 establishes a Rare Disease Advisory Council (RDAC) within the state, which if passed, would help to give a voice to the estimated 1-in-10 individuals living with a rare disease in Arizona.

Rare diseases are present across a broad spectrum of medical conditions. For patients living with one of the over 10,000 known rare conditions, it can take several years to receive an accurate diagnosis. Further, only a handful of rare diseases are well understood, with most not receiving sufficient attention or funding for research. This lack of awareness often contributes to the obstacles to timely treatment and care faced by many rare disease patients.

Creating an RDAC in Arizona will give the rare disease community a platform to help address challenges by serving as the advisory body on rare diseases to the Legislature and state departments. Additionally, the RDAC will be tasked with:

1) Convening public hearings, making inquiries, and soliciting comments from the public to assist with a first year landscape or survey of the unmet needs of Arizona;
2) Providing testimony and comments on pending legislation and rules that impact the state's rare disease community;
3) Consulting with experts on rare diseases to develop policy recommendations that improve patient access to, and quality of, rare disease specialists, affordable and comprehensive health care coverage, relevant diagnostics, timely treatment, and other needed services;
4) Researching and making recommendations to state agencies and health insurers that provide services to persons with rare diseases regarding the impact of orphan drug pricing, prior authorization, cost-sharing or other barriers to providing treatment and care for patients;
5) Evaluating and making recommendations to improve the Arizona Health Care Cost Containment System and State-regulated private health insurance coverage of drugs for rare disease patients; and
6) Identifying and distributing educational resources for health care providers to foster recognition and optimize treatment of rare disease in the state.

The RDAC represents enormous value to our organizations and the communities we serve by allowing them to directly engage with a diverse group of stakeholders interested in identifying and solving pressing challenges that Arizona's rare disease community faces. In addition, 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 will join thirty other states that have proven that the RDAC can be an invaluable resource. Those states are 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.

Once again, on behalf of the undersigned organizations, we urge your support of HB 2380 and swift passage of the bill. For any questions, please feel free to contact Lindsey Viscarra with the National Organization for Rare Disorders at lviscarra@rarediseases.org. Thank you for your consideration.

Sincerely,

List of Organizations