



October 8, 2021

The Honorable Doug Ducey
Governor of Arizona
1700 West Washington Street
Phoenix, Arizona 85007

Re: Support for a Rare Disease Advisory Council

Dear Governor Ducey,

On behalf of the 17 undersigned organizations representing individuals with rare diseases in Arizona, we urge you to issue an executive order to establish a Rare Disease Advisory Council (RDAC) in the state. Creating an RDAC would give a voice to the estimated 1-in-10 individuals living with a rare disease in Arizona and has broad support from the rare disease community.

The Arizona Rare Disease Advisory Council will give rare disease patients a unified voice in Arizona's state government. Additionally, the RDAC will be a valuable advisory body to elected officials and other state leaders on rare disease research, education, diagnosis, and treatment for the care of those with rare diseases. It will also be tasked with providing a report to your office, the Legislature, and other relevant agencies highlighting the Council's findings, activities, and recommendations for addressing the needs of rare disease patients 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. 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 would join twenty-one other states that have already enacted similar legislation in support of their rare disease community and proven that an RDAC can be an invaluable resource. Those states include Alabama, Connecticut, Florida, Illinois, Kentucky, Louisiana, Massachusetts, Minnesota, Missouri, New Hampshire, New Jersey, New York, Nevada, North Carolina, Ohio, Pennsylvania, South Carolina, Tennessee, Utah, Virginia, and West Virginia.

Once again, on behalf of the undersigned organizations, we urge you to create an RDAC through an executive order to support Arizona residents living with rare diseases. For any questions, please contact

Alyss Patel with the National Organization for Rare Disorders via email at apatel@rarediseases.org.
Thank you for your consideration.

Sincerely,

National Organization for Rare Disorders
American Cancer Society Cancer Action Network
American Kidney Fund
Arizona Chronic Care Together
Cancer Support Community Arizona
CFC International
Cystic Fibrosis Research Institute (CFRI)
Epilepsy Foundation - Arizona
Hemophilia Federation of America
IGA Nephropathy Foundation
International Pemphigus Pemphigoid Foundation
Leukemia & Lymphoma Society
March of Dimes
Neuropathy Action Foundation
Sick Cells
The ALS Association Arizona Chapter
The State of Black Arizona