NORD National Organization for Rare Disorders
EPILEPSY FOUNDATION ARIZONA
CANCER SUPPORT COMMUNITY ARIZONA
Parent Project Muscular Dystrophy JOIN THE FIGHT. END DUCHENNE.
myasthenia gravis association MGA
Neuropathy Action Foundation Awareness • Education • Empowerment
ACTnow
American Cancer Society Cancer Action Network fightcancer.org
THE BONNELL FOUNDATION: LIVING WITH CYSTIC FIBROSIS LIVE BREATHE INSPIRE Roadmap to CF thebonnellfoundation.org
AiARTHRITIS INTERNATIONAL FOUNDATION FOR AUTOIMMUNE & AUTOINFLAMMATORY ARTHRITIS
HFA Hemophilia Federation of America
CFRI Cystic Fibrosis Research Institute RESEARCH • EDUCATION • ADVOCACY • SUPPORT
EOSINOPHILIC & RARE DISEASE COOPERATIVE
Rare Disease Innovations Institute
ADRENAL INSUFFICIENCY UNITED
THE STATE OF BLACK ARIZONA
ARIZONA BLEEDING DISORDERS Formerly Arizona Hemophilia Association
UNITED MSD FOUNDATION
HCU NETWORK AMERICA
FANCONI CANCER FOUNDATION
ippf International Pemphigus & Pemphigoid Foundation
Dravet Syndrome Foundation
ARIZONA CHRONIC CARE TOGETHER
LEUKEMIA & LYMPHOMA SOCIETY
MLD foundation
ALS ASSOCIATION
GFPD GLOBAL FOUNDATION for PEROXISOMAL DISORDERS
CHI Congenital Hyperinsulinism International When too little sugar hurts, we help.
LITTLE HERCULES FOUNDATION
MELLIE J foundation
nnpdf NATIONAL NIEMANN PICK DISEASE FOUNDATION
APS1 The APS Type 1 Foundation Inc.
LUPUS and ALLIED DISEASES Association, Inc.

February 18, 2025

The Honorable Walt Blackman, Chair
House Committee on Government
Arizona State House of Representatives
1700 W. Washington St.
Phoenix, AZ 85007

**Re: Support for House Bill 2380**

Dear Chair Blackman and Members of the Committee on Government:

On behalf of the undersigned organizations representing individuals with rare diseases in Arizona, we urge your support of House Bill 2380 (Hernandez, A). HB2380 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 Americans living with a rare disease.

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 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 HB2380 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,

National Organization for Rare Disorders
American Cancer Society/Cancer Action Network
Adrenal Insufficiency United
Advocates for Compassionate Therapy Now
AiArthritis
APS Type 1 Foundation, Inc.
Arizona Bleeding Disorders
Arizona Chronic Care Together Coalition
Cancer Support Community Arizona
Cystic Fibrosis Research Institute
Congenital Hyperinsulinism International
Dravet Syndrome Foundation
Eosinophilic & Rare Disease Cooperative
Epilepsy Foundation of Arizona
Fanconi Cancer Foundation
Global Foundation for Peroxisomal Disorders
HCU Network America
Hemophilia Federation of America
International Pemphigus & Pemphigoid Foundation
Lupus & Allied Diseases Association
Little Hercules Foundation
Mellie J Foundation
MLD Foundation
Myasthenia Gravis Association
Neuropathy Action Foundation
Parent Project Muscular Dystrophy
Rare Disease Innovations Institute
The ALS Association
The Bonnell Foundation: Living with Cystic Fibrosis
The Leukemia & Lymphoma Society
The National Niemann-Pick Disease Foundation
The State of Black Arizona
United MSD Foundation