



March 11, 2024

The Honorable Rick Zbur  
 California State Assembly  
 California State Capitol  
 1021 O Street, Suite 4250  
 Sacramento, CA 95814

**Re: Support for Assembly Bill 2613**

Dear Assemblymember Zbur:

On behalf of the undersigned organizations representing individuals with rare diseases in California, thank you for your steadfast support of the rare disease community and your introduction of Assembly Bill 2613 (Zbur). AB 2613 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 California.

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 and effective treatment. 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 California will give rare disease patients a unified voice in state government to help address challenges that are faced by the rare disease community by serving as

the advisory body on rare diseases to the Legislature and state departments. Additionally, the RDAC will be tasked with: 1) evaluating and making recommendations to improve Medi-Cal and state-regulated private insurance coverage of medications that treat rare disease, as well as engaging the Medi-Cal Drug Use Review Board; 2) preparing a survey of the rare disease landscape in California, and convene public hearings to assist the Council in fulfilling its duties; 3) consulting with experts in rare diseases to develop policy recommendations; 4) creating and maintaining a website for the Council; 5) identifying and publishing a list of resources on said website; and 6) identifying areas of unmet need for research and opportunities for collaboration with stakeholders and RDACs in other states that can inform future studies and work done by the Council.

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 California'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 California government decisionmakers with one community voice.

In creating this council, California will join twenty-seven other states that have already enacted similar legislation in support of their rare disease community and have proven that the RDAC can be an invaluable resource. Those states are Alabama, Colorado, Connecticut, Delaware, Florida, Georgia, Illinois, Indiana, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Minnesota, 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 thank you for your introduction of AB 2613 and your commitment to the rare disease community. For any questions, please feel free to contact Lindsey Viscarra with the National Organization for Rare Disorders via email at [lviscarra@rarediseases.org](mailto:lviscarra@rarediseases.org). Thank you for your consideration.

Sincerely,

National Organization for Rare Disorders  
Cystic Fibrosis Research Institute  
Axis Advocacy  
AiArthritis: International Foundation for Autoimmune & Autoinflammatory Arthritis  
ALS Association  
APS Foundation of America, Inc.  
Cal Rare  
California Center for Rare Diseases at UCLA  
Center for Duchenne Muscular Dystrophy at UCLA  
Chronic Care Policy Alliance  
Dravet Syndrome Foundation  
Epilepsy Foundation of San Diego County  
Family Voices of California

Finding a Way  
Gaucher Community Alliance  
Hemophilia Council of California  
International Association of Hepatitis Task Forces  
International Pemphigus and Pemphigoid Foundation  
LGS Foundation  
Liver Coalition of San Diego  
Lupus Foundation of Southern California  
Lymphadema Advocacy Group  
Mellie J Foundation  
National MPS Society  
Necrotizing Enterocolitis (NEC) Society  
NephCure  
Neuropathy Action Foundation  
NMDP:  
Parkinson's Association of San Diego  
Project Alive  
RARE Science, Inc  
RASopathies Network  
Spastic Paraplegia Foundation  
The California Chronic Care Coalition  
TSC Alliance  
UC Irvine HD-Care