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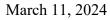












The Honorable Rick Zbur California State Assembly California State Capitol 1021 O Street, Suite 4250 Sacramento, CA 95814

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 1in-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 <a href="https://links.nih.gov/links/links.nih.gov/links.n

## 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