



February 15, 2022

The Honorable Susan Talamantes Eggman
Chair
Senate Subcommittee Three on Health and Human Services
Legislative Office Building – Room 502
Sacramento, California 95814

Re: Support for Creating a California Rare Disease Advisory Council

Dear Chair Talamantes Eggman,

On behalf of the 27 undersigned patient advocacy and health care organizations representing or treating individuals with rare diseases in California, we respectfully submit the following budget proposal to establish a Rare Disease Advisory Council (RDAC) within our state, which will give a voice to the estimated 1-in-10 Californian's living with a rare disease.

Any condition that affects fewer than 200,000 Americans is considered rare. Overall, there are more than 7,000 known rare diseases, affecting 25-30 million Americans across a broad spectrum of medical conditions. Rare disease patients face many unique challenges every day, from obtaining an accurate diagnosis and accessing medical specialists with knowledge of their condition, to battling for access to quality care and therapies, and fair insurance coverage of their treatment and care. However, due to small patient populations and the variety of rare diseases, it can be difficult for state government officials to have an in-depth understanding of the rare disease community's needs. This lack of awareness often contributes to the obstacles faced by rare disease patients and their loved ones.

During the 2021 legislative session, Senate Bill 247 (SB 247)¹, which would have created an RDAC, passed both chambers of the California Legislature unanimously and had broad support from the rare disease patient and provider community. Unfortunately, SB 247 was later vetoed² by Governor Newsom with comments directing stakeholders to create an RDAC through the budget process.

Attached to this budget proposal request is the California Assembly Fiscal Analysis for SB 247. Our organizations strongly believe the benefits provided through an RDAC far outweigh the expenses required for operating a council. Individuals living with rare diseases often have complex and costly needs for care, which can result in difficult hardships for rare disease patients and families. The financial burden of having a rare disease in the United States is significant. Investing in an RDAC could help reduce some of the challenges experienced by those in California's rare disease community while potentially offsetting costs.

An RDAC will give rare disease patients a unified voice in California state government and act as the advisory body on rare diseases to the Legislature and state departments that provide services to, or that are charged with the care of, rare disease patients. It will be tasked with collecting and disseminating best practices for rare disease care, advising on the most appropriate method to collect data and information concerning patients, and developing policy recommendations on issues relating to the quality and cost-effectiveness of, and access to, diagnosis, treatment, and services provided to rare disease patients. The RDAC represents enormous value to our organizations and the communities we serve by allowing us to directly engage with a diverse group of stakeholders interested in identifying and solving pressing challenges. Finally, the RDAC would 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 would join twenty-one other states that have already enacted similar legislation in support of their rare disease community and proven that the 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, we ask for your support of this budget proposal to enable the creation of a Rare Disease Advisory Council. Please contact Alyss Patel with the National Organization for Rare Disorders at apatel@rarediseases.org or Siri Vaeth with the Cystic Fibrosis Research Institute at svaeth@cfri.org if you have any questions.

Thank you for your consideration.

Sincerely,



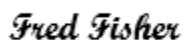
Alyss Patel
Western Region State Policy Manager
National Organization for Rare Disorders



Tiffany Westrich-Robertson, CEO
International Foundation for Autoimmune
& Autoinflammatory Arthritis (AiArthritis)

¹ California Legislative Information: SB-247 Rare Disease Advisory Council. Available at: [Bill Text - SB-247 Rare Disease Advisory Council. \(ca.gov\)](#)

² Veto Message to the Members of the California State Senate. Available at: [CAP14-20211005164120](#)



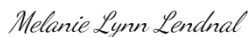
Fred Fisher, President & CEO
Golden West Chapter of the ALS Association



Autumn Ogden-Smith
Director, California State Legislation
American Cancer Society Cancer Action Network



Melissa King, Executive Director
Americans for Cures



Melanie Lendnal
Senior Director, State Policy
American Kidney Fund



Christina M Pohlman, President
APS Foundation of America, Inc.



Adrienne Shapiro, CEO
Axis Advocacy



Sophie Wallerstedt
Grassroots Campaign Manager
Be The Match/National Marrow Donor Program



Dena Feingold, Founder
Care Alliance Advocacy



John Pytel, President
California Coalition for PKU and Allied Disorders



Tuesdi Dyer, Executive Director
CFC International



Siri Vaeth, MSW, Executive Director
Cystic Fibrosis Research, Inc. (CFRI)



Rebekkah Halliwell, Executive Director
Epilepsy Foundation Los Angeles



Carlos Quesada, President & CEO
Epilepsy Foundation of Northern California



Wendy Urushima-Conn, President & CEO
Epilepsy Foundation of San Diego County



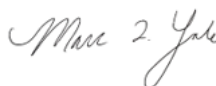
Lynne Kinst, Executive Director
Hemophilia Council of California



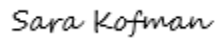
Michelle Kim, Executive Director
Hemophilia Foundation of Southern California



Stuart Miller
Director of Strategic Planning & Government Affairs
IGA Nephropathy Foundation of America



Marc Yale, IPPF Advocacy Research Coordinator
International Pemphigus Pemphigoid Foundation



Sara Kofman
Regional Director of Government Affairs
The Leukemia & Lymphoma Society



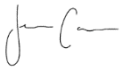
Scott Suckow, Executive Director
Liver Coalition of San Diego



Heather Ferguson, Executive Director
Lymphedema Advocacy Group



Kira Mann, CEO
MitoAction



Jennifer Canvasser, MSW
Founder and Executive Director



James Lee, Public Policy Chair
Neuropathy Action Foundation (NAF)



Emma Andelson, Program Manager
Sick Cells