



July 8, 2021

The Honorable Lorena Gonzalez  
 Chair  
 Assembly Appropriations Committee  
 State Capitol, Room 2114  
 Sacramento, California 95814

Re: Support for Senate Bill 247 (Eggman): Rare Disease Advisory Council

Dear Assembly Member Lorena Gonzalez,

On behalf of the 31 undersigned patient and health care provider organizations representing or treating millions of individuals with rare diseases in California, we thank you for placing Senate Bill 247 (SB 247) on the Assembly Appropriations Committee agenda for consideration. SB 247 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 the state of California.

Creating an RDAC will give rare disease patients a unified voice in California state government. Additionally, the RDAC will 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 also be tasked with adopting and implementing regulations, researching and determining the most appropriate method to collect data on rare diseases, and identifying best practices for rare disease care.

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 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, on behalf of the undersigned organizations and health care providers, we urge your swift consideration of SB 247 to enable the creation of a Rare Disease Advisory Council. Please feel free to contact Alyss Patel with the National Organization for Rare Disorders via email at [apatel@rarediseases.org](mailto:apatel@rarediseases.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)

**Fred Fisher**


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  
Director of State Policy and Advocacy  
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



Angela Ramirez Holmes, Founder/President  
CA Action Link for the Rare Diseases (Cal Rare)



Dena Feingold, Founder  
Care Alliance Advocacy



John Pytel  
California Coalition for PKU and Allied Disorders



Erin Foote Morgan, Interim Executive Director  
Chronic Disease Coalition



Tuesdi Dyer, Executive Director  
CFC International



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



Desiree Magee, Founder  
Daphne's Lamp



Rebekkah Halliwell, Executive Director  
Epilepsy Foundation Los Angeles



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



Cathy Teal, Executive Director  
FAIR Foundation



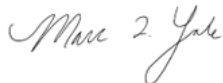
Sonji Wilkes, Vice President of Advocacy  
Hemophilia Federation of America



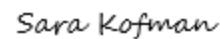
Stuart Miller  
Director of Strategic Planning and Government Affairs  
IGA Nephropathy Foundation of America



Jamie Sexton, Director of State Policy  
Immune Deficiency Foundation



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  
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Heather Ferguson, Executive Director  
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Emma Andelson, Program Manager  
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Jennifer Canvasser, MSW  
Founder and Executive Director  
Necrotizing Enterocolitis (NEC) Society

*Dominick V. Spatafora*

Dominick V. Spatafora, President  
Neuropathy Action Foundation (NAF)