



August 30, 2021

The Honorable Anthony Rendon
 Speaker
 California State Assembly
 Capitol Office, Room 219
 Sacramento, California 94249

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

Dear Speaker Rendon,

On behalf of the 31 undersigned patient and health care provider organizations representing or treating millions of individuals with rare diseases in California, we urge you to allow swift floor consideration of Senate Bill 247 (SB 247). 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 methods 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 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



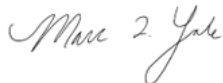
Sonji Wilkes, Vice President of Advocacy
Hemophilia Federation of America



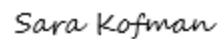
Stuart Miller
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IGA Nephropathy Foundation of America



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