September 9, 2021

The Honorable Gavin Newsom
Governor of California
State Capitol, First Floor
Sacramento, California 95814

Request for Signature: Senate Bill 247 (Eggman), Rare Disease Advisory Council

Dear Governor Newsom,

On behalf of the 32 undersigned patient and health care provider organizations representing or treating millions of individuals with rare diseases in California, we urge you to sign Senate Bill 247 (SB 247) into law. SB 247 would establish a Rare Disease Advisory Council (RDAC) and help give a voice to the estimated 1-in-10 individuals living with a rare disease in California. This legislation passed both chambers of the California Legislature unanimously and has broad support from the rare disease patient and provider community.

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 patient 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.

While the council is estimated to cost $678,000 annually, 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 and investing in an RDAC could help reduce some of these challenges experienced by those
in the rare disease community in our state.

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.

On behalf of the undersigned organizations, we urge you to sign SB 247 into law to support California
residents living with rare diseases. For any questions, 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
Melanie Lendnal
Director of State Policy and Advocacy
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Christina M Pohlman, President
APS Foundation of America, Inc.

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Axis Advocacy
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Be The Match/National Marrow Donor Program

Angela Ramirez Holmes, Founder/President  
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Dena Feingold, Founder  
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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  
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Wendy Urushima-Conn, President & CEO  
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Cathy Teal, Executive Director  
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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  
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Marc Yale, IPPF Advocacy Research Coordinator  
International Pemphigus Pemphigoid Foundation

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