NORD
ALS ASSOCIATION Golden West Chapter
Cancer Action Network American Cancer Society
Americans for Cures
American Kidney Fund FIGHTING ON ALL FRONTS
APS Foundation of America, Inc Celebrating 15 years of service
Axis Advocacy Sickle Cell Disease Community and Support
NATIONAL MARROW DONOR PROGRAM BE THE MATCH
CALRARE California Action Link for Rare Diseases
Chronic Disease Coalition
cfri Cystic Fibrosis Research Inc.
FAIR FOUNDATION
HFA Hemophilia Federation of America
IDF Immune Deficiency Foundation
IGA NEPHROPATHY FOUNDATION Dedicated to finding a cure.
LEUKEMIA & LYMPHOMA SOCIETY
LIVER COALITION OF SAN DIEGO
LYMPHEDEMA ADVOCACY GROUP
MiORA
NEC SOCIETY Building a World Without NEC
NEUROMUSCULAR DISEASE FOUNDATION JOIN THE GLOBAL EFFORT TO CURE NEUROMUSCULAR DISEASES
SICK CELLS

April 30, 2021

The Honorable Anthony J. Portantino
Chair
Senate Appropriations Committee
State Capitol, Room 2206
Sacramento, CA 95814

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

Dear Senator Portantino,

On behalf of the undersigned organizations representing individuals with rare diseases in California, we thank you for your work during COVID-19 and urge you to swiftly move Senate Bill 247 (SB 247) through your Committee. SB 247 establishes a rare disease advisory council (RDAC) and ombudsperson 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.

Though we are facing unprecedented times during the COVID-19 pandemic, we write to urge that SB 247 is passed this session. Rare diseases are present across a broad spectrum of medical conditions and their needs have not subsided during this crisis. For example, across the country, 74% of rare disease patients have had a medical appointment cancelled due to COVID-19 and approximately 70% are concerned about medication and medical supply shortages.[1]

Creating an RDAC and ombudsperson in California will give rare disease patients a unified voice in California state government. Additionally, the RDAC will be a valuable advisory body to elected officials and other state leaders on rare disease research, beneficiary access to treatments, and best practices for

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[1] https://rarediseases.org/new-community-survey-from-nord-reveals-significant-impact-of-covid-19-on-americans-living-with-rare-diseases/

the care of those with rare diseases. It will also be tasked with creating a rare disease plan for the state and developing methods to publicize the profile of the social and economic burden of rare diseases to ensure health care providers are informed.

The RDAC and ombudsperson 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 seventeen 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, Illinois, Kentucky, Massachusetts, Minnesota, Missouri, New Hampshire, New York, Nevada, North Carolina, Ohio, Pennsylvania, Tennessee, Utah, Virginia and West Virginia.

Once again, on behalf of the undersigned organizations, we thank you for your consideration of SB 247 that would enable the creation of a Rare Disease Advisory Council and ombudsperson. Please support this legislation by swiftly moving it through your Committee to give a voice to 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. Thank you for your consideration.

Alyss Patel

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

Fred Fisher

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

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Stuart Miller

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

Jamie Sexton, Director of State Policy
Immune Deficiency Foundation

Dana Bacon, Regional Government Affairs Director
The Leukemia & Lymphoma Society

Scott Suckow, Executive Director
Liver Coalition of San Diego

Heather Ferguson

Heather Ferguson, Executive Director
Lymphedema Advocacy Group

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Nancy Lurie

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Emma Andelson

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CC: Members of the Senate Appropriations Committee