



Alone we are rare. Together we are strong.®

March 6, 2025

The Honorable Jesse Gabriel  
Chair, Assembly Budget Committee  
1021 O Street, Suite 8230  
Sacramento, CA 95814

The Honorable Dawn Addis  
Chair, Assembly Budget Committee No. 1 on Health  
1021 O Street, Suite 8230  
Sacramento, CA 95814

Dear Chairs Gabriel and Addis and Members of the Assembly Budget Committee,

On behalf of the estimated 1-in-10 individuals living with one of the more than 10,000 known rare diseases, the National Organization for Rare Disorders (NORD) urges your support for funding for AB 2613 (Zbur, 2024), which created the Jacqueline Marie Zbur Rare Disease Advisory Council (RDAC) in California. Passed unanimously by the Assembly and Senate, and signed into law by Governor Newsom in September 2024, the Jacqueline Marie Zbur RDAC will serve as a vital platform to amplify the voices of millions of Californians living with a rare disease.

Rare disease patients in California face unique challenges every day, from obtaining an accurate diagnosis and accessing medical specialists with knowledge of their condition, to battling for fair insurance coverage of their treatment and care. The California RDAC will help address these issues by providing a forum for stakeholders across the state knowledgeable about the needs of rare disease patients to make recommendations on how to improve public policy that impacts our community.

The RDAC will be a valuable advisory body to elected officials and other state leaders on research, education, diagnosis, care, and treatment for rare diseases. It is tasked with providing an annual report, highlighting the Council's findings, activities, and recommendations for addressing the needs of rare disease patients in the state. The RDAC will help relieve some of the burden on the state by expeditiously delivering direct feedback, solutions, and resources to California government decision makers with one community voice.

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The California RDAC can only become a reality with your Committee's appropriations support. The budget request for the program is \$2.6 million over the 3-year program period and aligns with the recommendation from Assembly Appropriations' fiscal analysis. The funding necessary to implement the Council has been requested by Assemblymember Zbur, and we appreciate your consideration of his request, which we believe this is an appropriate level of funding for this vital program to fulfill its mandated duties and support rare disease community.

NORD urges you to grant the budget request, allowing the California RDAC to join the 29 other states with functioning councils. NORD and the rare disease community appreciate your commitment to those living with rare diseases and their caregivers.

Sincerely,



Lindsey Viscarra  
State Policy Manager, Western Region  
National Organization for Rare Disorders

CC: Leah Barber, Director of Grassroots Advocacy, NORD



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