



Alone we are rare. Together we are strong.®

July 18, 2024

The Honorable Anna Caballero, Chair
The Honorable Brian Jones, Vice-Chair
Committee on Appropriations
California State Senate
State Capitol, Room 412
Sacramento, CA 95814

Dear Chair Caballero, Vice-Chair Jones, and Members of the Committee on Appropriations,

On behalf of the 1-in-10 individuals in California living with one of the more than 10,000 known rare diseases, the National Organization for Rare Disorders (NORD) urges your support for Assembly Bill 2613 (Zbur), which would establish a Rare Disease Advisory Council (RDAC) in California.

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 would 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 those with rare diseases. It will also be tasked with providing a report to the Governor and the Legislature, highlighting the Council's findings, activities, and recommendations for addressing the needs of rare disease patients in the state. The RDAC would 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.

In 2024, AB2613 has passed with no opposition through the Assembly Health Committee, Assembly Appropriations Committee, the full California State Assembly, and Senate Health Committee.

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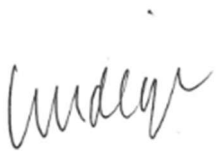
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In creating this council, California would join twenty-eight other states (Alabama, Colorado, Connecticut, Delaware, Florida, Georgia, Illinois, Indiana, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Minnesota, Mississippi, Missouri, Nevada, New Hampshire, New Jersey, New York, North Carolina, Ohio, Pennsylvania, South Carolina, Tennessee, Utah, Virginia, and West Virginia) that have already enacted similar legislation in support of their rare disease community and proven that an RDAC can be an invaluable resource. It's essential that California joins this group and provides leadership in the rare disease landscape.

NORD urges your support for this important legislation and for swift consideration before your Committee. NORD and the rare disease community appreciate your commitment to providing a voice for those living with rare diseases and their caregivers in California.

Sincerely,



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