



Alone we are rare. Together we are strong.®

August 29, 2024

The Honorable Gavin Newsom
Governor
State of California
1021 O Street, Suite 9000
Sacramento, CA 95814

Dear Governor Newsom,

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 signature on 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 rare diseases. It will also be 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 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.

AB2613 passed through both the Assembly and the Senate unopposed and with zero no votes. It has enjoyed broad bipartisan support, and we are thankful for the hard work of your staff and staff at the Department of Public Health on AB2613. We applaud their assistance in making this legislation the very best it can be for the rare disease community of California.

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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.

NORD urges your support for this important legislation by signing it into law. 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