April 2, 2024

The Honorable Mia Bonta, Chair

The Honorable Marie Waldron, Vice Chair

Assembly Committee on Health

1020 N Street, Room 390

Sacramento, CA 95814

**Re: Support for Assembly Bill 2613**

Dear Chair Bonta, Vice Chair Waldron, and Members of the Assembly Committee on Health:

As a rare disease patient/caregiver in California, I urge your support of Assembly Bill 2613 (Zbur). AB 2613 establishes a Rare Disease Advisory Council (RDAC) 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 California.

[insert your rare disease story here]

For patients living with one of the over 10,000 known rare conditions, it can take several years to receive an accurate diagnosis and effective treatment. Further, only a handful of rare diseases are well understood, with most not receiving sufficient attention or funding for research. This lack of awareness often contributes to the obstacles to timely treatment and care faced by many rare disease patients.

Our goal for the Council is to raise awareness about rare disorders, provide valuable knowledge and information to policymakers, and to be a resource to individuals and families throughout their journey with a rare disease, as well as to medical providers who are working to support a patient in their diagnosis.

The RDAC will provide enormous benefit to the state legislature and other departments by allowing them to directly engage with a diverse group of stakeholders interested in identifying and solving pressing challenges that California’s rare disease community faces. 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.

Once again, I urge your support of AB2613. It is essential that the rare disease community have a voice in state government. Thank you for your consideration.

Sincerely,

[your name and organization if applicable]