RARE READY
A GENETIC CONDITION COALITION

June 11, 2025

The Honorable Caroline Menjivar, Chair
Senate Health Committee
1021 O Street, Suite 6630
Sacramento, CA 95814

Dear Chair Menjivar and Members of the Senate Health Committee:

The Rare & Ready Coalition would like to express our strong support of AB 539, which would require prior authorization for healthcare services to remain valid for at least one year or throughout the course of the prescribed treatment, if less than one year.

Rare & Ready is a coalition of 80 nonprofit organizations working to ensure rare disease patients get timely access to the care they need and deserve. We represent rare disease grassroots patient organizations from across the U.S. that include patients, caregivers and advocates across California. Our efforts are not disease- or treatment-specific; rather, we seek to address shared concerns of the broader rare disease community.

AB 539 presents an opportunity to provide rare disease patients with the lifesaving medications they need in a timely manner – without the unnecessary, extra paperwork.

According to the NIH, a rare disease is defined as a condition that affects fewer than 200,000 people in the United States. There are approximately 10,000 rare diseases affecting an estimated 4 million Californians.

Families impacted by rare diseases and rare conditions often face an extensive and harrowing journey to find a diagnosis and optimal treatment -- if one exists. These treatments, prescribed by specialists and experts in rare disease, are a lifeline to improved quality of life and should not be subject to burdensome delays and additional bureaucratic hurdles imposed by multiple prior authorization requirements.

Decisions regarding care must be left up to patients and their physicians. AB 539 empowers patient and physician decision-making by reducing the number of times a physician's expert opinion can be second-guessed by burdensome prior authorization processes throughout the year.

Prior authorizations are harmful to adherence.
A study of Medicare Part D claims found that a new prior authorization policy on an established drug regimen is associated with increased probability of discontinued and delayed care.

While prior authorizations are a utilization management tool designed to contain costs by limiting use of healthcare services, excessive utilization management, such as additional prior authorizations, can cause healthcare costs to skyrocket.

If rare disease patients are faced with delays in medication, forced to ration treatment while they await a prior authorization decision or experience a denial for a treatment which has previously proven to be successful, they may require hospitalizations and use additional healthcare services that could be avoided with timely access to treatment.

Prior authorization disproportionately penalizes people with rare diseases. The prior authorization process requires a patient's prescribing physician to meet with a representative from an insurance company to prove the "medical necessity" of a prescribed treatment or service.

People living with rare, genetic conditions often have limited treatment options -- with 95% of such conditions lacking any FDA-approved therapies. Among our membership, we represent rare conditions which may only have one available option for treatment or only one provider in the entire state who specializes in the treatment modality.

Considering these circumstances, it is unreasonable to assume that the "peer" physician will always be well-versed in the complexities of rare disease when deciding the fate of a prior authorization request.

In conclusion, on behalf of the rare disease community in California, we urge your support of AB 539. With each prior authorization, the prospect of harm is introduced to patients, especially those demonstrating stability on their current treatment. We believe that one prior authorization per year is more than enough.

This bill lays a foundation for more equitable treatment of rare diseases, empowers experts in rare disease to make the right decisions, and reduces barriers and stress imposed on individuals already facing a journey of resilience living with a rare disease.

Sincerely,

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