NORD®
National Organization for Rare Disorders

Alone we are rare. Together we are strong.®

August 28, 2026

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

RE: Request for Signature AB1887 – Prescription Drug Coverage for Rare Diseases

Dear Governor Newsom,

On behalf of the 1-in-10 Californians living with one of the approximately 10,000 known rare diseases, the National Organization for Rare Disorders (NORD) urges you to sign Assembly Bill 1887 (AB 1887) into law. AB1887 would prohibit most California health plans and insurers from requiring prior authorization or step therapy for FDA-approved drugs prescribed for rare diseases by January 2027, unless a biosimilar or generic is available, when prescribed by and appropriate specialist based on medical necessity. We believe this would improve access to treatments for rare disease patients in your state.

Founded in 1983, the National Organization for Rare Disorders (NORD®) is the pioneer patient advocacy organization dedicated to improving the health and lives of over 30 million Americans living with rare diseases, including the approximately 4 million living in California. In partnership with more than 350 disease-specific member patient organizations, NORD drives progress in rare disease research, care, and policy. We believe that all patients should have access to quality, accessible and affordable health coverage that is best suited to their medical needs.

California has long led the way in advancing patient-centric policy, receiving an A on NORD's State Scorecard. With your signature, AB 1887 would add another level of support for patients with rare diseases in the state.

While 90% of rare diseases have no U.S. Food and Drug Administration (FDA)-approved treatment, some rare disease patients are fortunate to have an FDA-approved medication intended to treat their rare disorder or other co-morbidities.

Prior Authorization is a tool that can control costs and prevent the overuse of health care services. However, when used improperly or without consideration of a patient's unique medical situation or history, utilization management protocols can delay necessary treatment by weeks or even months. Particularly for patients with rare diseases, delayed access to treatment can lead to medical setbacks, disease progression, loss of function, and even hospitalizations.

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Step Therapy, also known as step protocols or fail first requirements, is a process by which insurers require patients to take one or more alternative medications before they can access the medicine initially. While meant to also control costs, this has been increasingly applied to patients with little regard for the medical situation or treatment history. When used inappropriately, step therapy protocols can delay necessary treatment and lead to adverse reactions that ultimately increase health care costs, not lower them.

AB 1887 would ensure that when a specialist prescribes an FDA-approved rare disease treatment, patients can access it without unnecessary delays. It will speed access to critical therapies, prevent treatment interruptions, and reduce administrative waste. Most importantly, it will go a long way to protect patients with rare diseases. Please sign AB 1887.

Sincerely,

Kathryn Lowell

Kathryn Lowell
Executive Vice President, Government Affairs
National Organization for Rare Disorders