



September 17, 2021

The Honorable Gavin Newsom
Governor of California
State Capitol, First Floor
Sacramento, California 95814

Request for Signature: Assembly Bill 347 (Arambula)

Dear Governor Newsom,

On behalf of the 1-in-10 individuals living in California with one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD), urges you to sign Assembly Bill 347 (AB 347) into law. AB 347 would implement common-sense patient protections pertaining to utilization management. This legislation passed both chambers with overwhelming bipartisan support.

NORD is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. We are committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services. NORD believes strongly that all patients deserve the medical care that is best suited for their medical situation and will give them the best results. Based on the reports we receive from individuals affected by rare diseases, utilization management is increasingly being applied by health plans in California with little regard for a patient's treatment history and specific medical needs.

Utilization management, which includes prior authorization and step therapy, is a set of tools that insurers use to manage the cost of health care by evaluating the necessity of services and therapies. For example, step therapy, also known as "fail first," is an insurance company practice that requires patients to try and fail one or several medications chosen by their insurer before allowing them to take the medicine prescribed by their provider. Step therapy protocols vary widely among insurers. Navigating an appeal can be confusing and time consuming for patients and their health care providers, sometimes taking weeks or even months. This process of prolonging ineffective treatment and delaying access to the right treatment – especially for patients living with serious or chronic illnesses – can lead to medical setbacks, disease progression, loss of function and even hospitalizations.

We ask your support of AB 347 to allow patients better access to the appropriate treatments prescribed by their health care providers. This would be accomplished by:

- Ensuring step therapy protocols are based on widely-accepted medical and clinical guidelines;



- Creating a clear and expeditious appeals process – requiring a reply within 24 hours for an emergency or 72 hours for a non-emergency;
- Protecting patients who have already tried and failed a drug or for whom a drug is expected to be ineffective;
- Protecting patients whose conditions are well-controlled on a prescription from being required to try a new medication against their provider’s recommendation or for whom the medication is contraindicated or likely to cause harm; and
- Protecting patients when their provider recommends a specific medication due to medical necessity.

It is important to note that AB 347 does not ban the use of step therapy. However, in order to guarantee patient safety, California needs to ensure that utilization management policies do not interfere with appropriate care for rare disease patients and families. By supporting AB 347, you will be protecting patients, while still enabling health plans to achieve the cost saving benefits of step therapy when appropriate. Given the additional challenges of the COVID-19 pandemic, now is a logical time to pass step therapy protections into law to avoid some of the unnecessary burdens on patients, providers and the health care system that could be prevented with appropriate and timely care.

Once again, on behalf of the California rare disease community, we urge you to sign AB 347 into law. For any questions, please feel free to contact Alyss Patel at apatel@rarediseases.org. Thank you for your consideration.

Sincerely,

Alyss Patel
State Policy Manager, Western Region
National Organization for Rare Disorders