Office of Senate Floor Analyses
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THIRD READING

Bill No: AB 1887
Author: Zbur (D), et al.
Amended: 8/21/26 in Senate
Vote: 21

SENATE HEALTH COMMITTEE: 10-0, 7/1/26
AYES: Weber Pierson, Valladares, Caballero, Durazo, Gonzalez, Grove, Menjivar, Padilla, Pérez, Smallwood-Cuevas
NO VOTE RECORDED: Rubio

SENATE APPROPRIATIONS COMMITTEE: 7-0, 8/13/26
AYES: Cervantes, Seyarto, Cabaldon, Dahle, Grayson, Richardson, Wahab

ASSEMBLY FLOOR: 77-0, 5/27/26 - See last page for vote

SUBJECT: Prescription drug coverage for rare diseases

SOURCE: California Chronic Care Coalition

DIGEST: This bill (1) requires prior authorization for prescription drugs prescribed for the treatment of a rare disease to be completed within 30 days of the initial request by a provider if the drug is the only U.S. Food and Drug Administration-approved treatment for the rare disease; and (2) requires approval of the prescription if the 30-day timeline is not met due to an unresolved decision or dispute.

Senate Floor Amendments of 8/21/2026 clarify that this bill does not affect the timelines required for prescription drug prior authorization in current law and add the appropriate cross-references.

ANALYSIS:

Existing law:

1) Establishes the Department of Managed Health Care (DMHC) to regulate health plans under the Knox-Keene Health Care Service Plan Act of 1975 and the California Department of Insurance (CDI) to regulate health and other insurance. [Health & Safety Code (HSC) §1340, et seq. and Insurance Code (INS) §106, et seq.]

2) Requires health plans and insurers that perform utilization review (UR) or utilization management (UM) functions, or who delegate these functions to other contracting providers, to make decisions to approve, modify, or deny, a health service in a timely fashion appropriate for the enrollee's/insured's condition, as specified. [HSC §1367.01 and INS §10123.135]

3) Requires DMHC and CDI to require health plans and insurers to establish and maintain a prior authorization application programming interface for enrollees/insureds and contracted providers. [HSC §1374.196 and INS §10133.12]

4) Requires a health plan or insurer to accept only a standardized prior authorization form developed by DMHC and CDI, or an electronic prior authorization process when requiring prior authorization for prescription drugs. [HSC §1367.241 and INS §10123.201]

5) Requires a prior authorization exception to be deemed granted if a health plan or insurer fails to respond, within 72 hours upon the receipt of a completed form, or within 24 hours if exigent circumstances exist. Defines "exigent circumstances" as when an enrollee/insured is suffering from a health condition that may seriously jeopardize their life, health, or ability to regain maximum function, or when an enrollee/insured is undergoing a current course of treatment using a nonformulary drug. [HSC §1367.241 and INS §10123.191]

6) Excludes, from health plan or insurer prior authorization requirements, covered health care services that have been approved by the plan/insurer 90% or more times, as determined by DMHC or CDI after reporting and evaluation. Excludes specified services, including outpatient drugs on tier three or tier four of a formulary. Sunsets on January 1, 2034. [HSC §1367.025 and INS §10133.52]

This bill:

1) Defines "rare disease" as a disease that affects fewer than 200,000 people in the U.S.

2) Requires a health plan or insurer to complete prior authorization within 30 days upon the initial request for a prescription approved by the U.S. Food and Drug

Administration (FDA) for the treatment of a rare disease if the drug is prescribed by a specialist with expertise in the condition or disease being treated, the specialist has determined the drug is medically necessary, and the drug is the only FDA-approved treatment for the rare disease.

3) Requires the prior authorization to be immediately approved if, at the end of the 30-day period, a decision to approve or deny the prior authorization has not been made or a dispute between the plan and provider or enrollee is ongoing.

Background

According to the author of this bill:

> Families living with rare diseases in California often spend years searching for a diagnosis and an effective treatment, only to be forced to "fail first" on less appropriate therapies or wait weeks or months for prior authorization from their health plan before they can start the one FDA-approved drug that can slow or stop their condition. These insurer-imposed delays are unnecessary when a specialist has prescribed an FDA approved therapy based on medical necessity, and in some cases, they are reckless and life threatening. This bill aims to address this by accelerating prior authorization for rare disease treatments when prescribed by an appropriate specialist based on medical necessity. California is a global leader in rare disease research and innovation; this bill ensures that the people who rely on these breakthroughs can access them without bureaucratic obstacles, improving health outcomes and quality of life for some of our most vulnerable residents.

Rare diseases and treatment. According to the National Human Genome Research Institute (NHGRI), and as defined in the federal Food, Drug, and Cosmetic Act, rare diseases are those that affect fewer than 200,000 people in the U.S. There are over 7,000 rare diseases, according to the California Center for Rare Diseases at UCLA, including diseases like cystic fibrosis, Huntington's disease, Duchenne muscular dystrophy, phenylketonuria, and sickle cell disease. According to the NHGRI, about 80% of rare diseases are genetic. Because many rare diseases are genetic, approximately 75% of rare diseases manifest during childhood, and 50% of patients with rare diseases are children, according to a 2025 review in *ACR Open Rheumatology*.

The Orphan Drug Act of 1983 created an orphan drug designation that offers financial incentives for pharmaceutical manufacturers to invest in research and development for rare diseases, which, by definition, have a small market.

According to a 2024 policy brief from the Congressional Research Service, since the enactment of the Orphan Drug Act, over 500 rare disease drugs have been approved. About 5% of rare diseases have an FDA-approved drug, according to a 2023 study in the *Orphanet Journal of Rare Diseases*, and up to 15% have least one promising drug candidate in the pipeline for treatment, diagnosis, or prevention.

Prior authorization in California. Prior authorization is a form of UR or UM in which the payer grants permission for the use of the medication after the clinician prescribes it, before the patient can begin treatment. For prescription drugs, state-regulated health plans and insurers must use a standardized prior authorization form and decide requests within 72 hours (or 24 hours for urgent cases), or the request is automatically approved. If additional information is needed, the plan must notify the provider within those same timeframes or the request is deemed approved. Once the missing information is received, the 72- or 24-hour review period restarts. If no decision or request for more information is provided within the required timeframe, the prior authorization is approved for the full prescription, including refills. Denials must include notice to the provider and enrollee/insured of an external appeals process. Because rare disease drugs are specialty drugs, virtually all of them require prior authorization.

Exemption from SB 306. Concerns about prior authorization's effectiveness, administrative burden, and patient outcomes led the Legislature to pass SB 306 (Becker, Chapter 408, Statutes of 2025), which, beginning in 2028, eliminates prior authorization for services that receive approval at least 90% of the time, as determined by DMHC and CDI. Specialty outpatient drugs on Tier 4 of a drug formulary, like those for rare diseases, are exempt from the SB 306 process.

California Health Benefits Review Program (CHBRP) analysis. Key findings include:

- *Coverage impacts and enrollees covered*. CHBRP estimates that 13.8 million Californians (36.2% of the state) have CDI- and DMHC-regulated insurance subject to this bill. Medi-Cal managed care plans are excluded from this bill.
- *Medical effectiveness.* CHBRP did not find any literature on the impacts of UM on the use of prescription drugs for rare diseases. However, there is some evidence that UM leads to delays in access to prescription drugs to treat non-rare diseases, causing delays in the initiation of prescription drug treatment ranging from an average of four to 44 days. Furthermore, there is some evidence from retrospective studies that UM for prescription drugs for non-rare diseases are related to unnecessary hospitalizations, emergency department visits, and increased morbidity resulting from delays in prescription drug

treatments. Lastly, CHBRP found conflicting evidence on the impact of UM on denials of prescription drug treatments for non-rare diseases.

- *Utilization*. CHBRP estimated that the removal of UM would result in 8,200 people starting an additional 17,000 new prescriptions for a medication to treat a rare disease within a plan benefit year, increasing utilization of small-molecule drugs by 4% for those drugs available at the pharmacy and by 8% for those administered by a physician. Utilization of biologics is estimated to increase by 2% for those available through the pharmacy and 2% for those administered by a physician.
- *Medi-Cal.* This bill does not apply to Medi-Cal plans.
- *Impact on premiums.* Eliminating an estimated 60-day delay for new rare disease prescriptions is estimated to increase total annual premiums by $148 million, with $96.1 million paid by employers and $51.7 million paid by enrollees/insureds. Average annual enrollee/insured premiums are estimated to increase by between $1.49 and $10.69, depending on the insurance market, with the largest increase in the individual market.
- *Impact on cost-sharing.* Because this bill is expected to provide two additional 30-day prescriptions per year for affected enrollees/insureds, cost-sharing for those taking those drugs will increase. The annual average cost-sharing for those with drugs subject to this bill is expected to increase by $900 to $1,200, depending on the insurance market, with the largest cost-sharing increases in the individual market.
- *Essential health benefits (EHBs).* Because this bill does not require coverage for any additional prescription drugs, it does not exceed the current definition of EHBs in California.
- *Public health.* CHBRP estimates no measurable population-level public health impacts of this bill, although there may be meaningful quality-of-life improvements for the individuals with rare diseases who would be able to access their treatments sooner, and for clinicians, patients, and families who would be able to avoid protracted prior authorization processes.

FISCAL EFFECT: Appropriation: No Fiscal Com.: Yes Local: Yes

According to the Senate Appropriations Committee, there are unknown and likely minor ongoing costs for DMHC and CDI for state administration, as well as unknown ongoing General Fund costs, potentially in the low millions, due to increases in CalPERS plan premiums.

SUPPORT: (Verified 8/21/26)

California Chronic Care Coalition (source)

Arginase 1 Deficiency Foundation
ALS Association
Alliance for Patient Access
Association for Creatine Deficiencies
Biocom California
Bleeding Disorders Council of California
Breathe California
Breathe Southern California
California Chronic Care Coalition
California Life Sciences Association
California Pharmacists Association
California Rheumatology Alliance
Cedars-Sinai
Children's Specialty Care Coalition
Chronic Disease Coalition
CSNK2A1 Foundation
Cure SMA
Cystic Fibrosis Research, Inc.
Dravet Syndrome Foundation
EB Research Partnership
Flok Health
Hemophilia Foundation of Southern California
Herrera & Company
Infusion Access Foundation
International Foundation for Autoimmune and Autoinflammatory Arthritis
International Pemphigus and Pemphigoid Foundation
Little Legs Big Heart Foundation
National Association of Pediatric Nurse Practitioners
National Ataxia Foundation
National Kidney Foundation
National Organization for Rare Disorders
National PKU Alliance
Neuropathy Action Foundation
Overcome Lupus
Project Alive
Psychiatric Physicians Alliance of California
Rare & Ready Coalition
RareRising
The EveryLife Foundation for Rare Diseases
TSC Alliance

OPPOSITION: (Verified 8/21/26)

Association of California Life & Health Insurance Companies
California Association of Health Plans
California Chamber of Commerce

ARGUMENTS IN SUPPORT: The California Chronic Care Coalition (CCCC), the sponsors of this bill, share that many rare disease patients see an average of 17 providers over more than six years before receiving an accurate diagnosis, and the avoidable costs associated with those delays range from $86,000 to $517,000 per patient. The CCCC states that this bill stops prolonged review from standing between a patient and the treatment a specialist has already determined is medically necessary, and many other patient advocacy and disease research groups agree that this bill offers a targeted solution to protect access to rare disease therapies while allowing plans to apply UM controls in situations where true alternatives exist. Many groups share specific examples of difficulties accessing treatments. The Dravet Syndrome Foundation shares that access to the three approved medications for the disease is limited by prior authorization and step therapy requirements, which may result in increased seizure activity, emergency hospitalizations, and long-term impacts. The Hemophilia Foundation of Southern California shares that they have heard directly from families who have had to postpone or miss treatments while waiting for approvals—putting their health, mobility, and quality of life at risk. The ALS Association writes that many patients continue to face significant barriers to accessing the first FDA-approved treatment for a rare and particularly aggressive form of ALS, including prior authorization delays, repeated requests for additional documentation, coverage denials, and lengthy appeals processes. Provider groups state that patients face long diagnostic journeys and uncertainty, and additional administrative delays can lead to disease progression, avoidable complications, and interruptions in care. A provider from the National Association of Pediatric Nurse Practitioners states that it is frustrating to see pediatric patients go weeks without enzyme replacement infusions due to delayed prior authorization. Lastly, The Rare and Ready Coalition and Little Legs Big Heart Foundation supports the bill but also asks the Committee to consider an amendment removing prior authorization requirements for patients age 18 and under.

ARGUMENTS IN OPPOSITION: The Association of California Life and Health Insurance Companies (ACLHIC) and California Association of Health Plans (CAHP) oppose the $148 million projected increase in health insurance premiums, particularly given that health plans already cover these medications. They also oppose this bill's 30-day review period for prior authorization requests,

arguing that because prior authorization requests for rare disease treatments are typically used as a verification tool rather than a mechanism to deny care, the language around automatic approval should be removed to avoid setting a precedent of preferential treatment for one class of expensive drugs. CAHP/ACLHIC also point out that because this bill does not require a provider's request to be complete or to include all clinically necessary information before the clock begins, it may not hold all parties equally accountable for ensuring patients receive safe and appropriate care. The California Chamber of Commerce also opposes the bill due to the impacts on insurance premiums for employers and employees. They highlight that employer health care premiums are estimated to increase by over $96 million per year, and the largest increases will be seen in small-group (small businesses with fewer than 51 employees) and individual markets. These must also be viewed in the context of consistent increases year after year, partially due to benefit mandates. They share that the average premium for family coverage has increased 20% over the five years prior to the publication of the 2022 Kaiser Family Foundation Employer Health Benefits Survey.

ASSEMBLY FLOOR: 77-0, 5/27/26
AYES: Addis, Aguiar-Curry, Ahrens, Alanis, Alvarez, Arambula, Ávila Farías, Bains, Bauer-Kahan, Bennett, Berman, Boerner, Bonta, Bryan, Calderon, Caloza, Carrillo, Castillo, Chen, Connolly, Davies, DeMaio, Dixon, Elhawary, Ellis, Flora, Fong, Gabriel, Gallagher, Garcia, Gipson, Jeff Gonzalez, Mark González, Hadwick, Haney, Harabedian, Hart, Hoover, Irwin, Jackson, Johnson, Kalra, Krell, Lackey, Lee, Lowenthal, Macedo, McKinnor, Muratsuchi, Nguyen, Ortega, Pacheco, Papan, Patel, Patterson, Pellerin, Petrie-Norris, Ramos, Ransom, Michelle Rodriguez, Rogers, Blanca Rubio, Sanchez, Schiavo, Schultz, Sharp-Collins, Solache, Soria, Stefani, Ta, Valencia, Wallis, Ward, Wicks, Wilson, Zbur, Rivas
NO VOTE RECORDED: Quirk-Silva, Celeste Rodriguez, Tangipa

Prepared by: Natalie Gehred / HEALTH / (916) 651-4111
8/24/26 13:30:58

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