ASSEMBLY THIRD READING
AB 1887 (Zbur)
As Amended May 19, 2026
Majority vote

SUMMARY

Prohibits step therapy for prescription drugs for the treatment of a rare disease, as specified. Requires prior authorization (PA) or utilization review (UR) for prescription drugs prescribed for the treatment of a rare disease to be complete within 30 days of the initial request by a provider. Requires approval of the prescription if the 30-day timeline is not met, as specified.

Major Provisions

COMMENTS

Rare diseases are medical disorders, illnesses, or conditions that affect a relatively small number of individuals. According to the National Institutes of Health and the Orphan Drug Act, rare diseases are those that affect fewer than 200,000 people in the United States. Rare diseases are often chronic, serious, and progressive diseases that are life-threatening or life-limiting. Signs of rare diseases are often present at birth or in childhood, although there is a subset of rare diseases that do not appear until adulthood. Rare diseases can affect any organ system and might affect multiple body systems. Approximately 80% of rare diseases are caused by genetic mutations and may be inherited but can also be new mutations. Rare diseases may also be caused by infections or environmental factors. There are an estimated 5,000 to over 10,000 rare diseases in the United States. It is estimated that in 10 Californians, or close to four million Californians, are living with a rare disease, based on national estimates. Only 5% of the 5,000 to 10,000 rare diseases currently have U.S. Food and Drug Administration (FDA)-approved drugs indicated for their treatment. The time to receive a correct diagnosis of a rare disease can vary widely, with four to five years as the average.

California Health Benefits Review Program (CHBRP). CHBRP was created in response to AB 1996 (Thomson), Chapter 795, Statutes of 2002, which requests the University of California to assess legislation proposing a mandated benefit or service and prepare a written analysis with relevant data on the medical, economic, and public health impacts of proposed health plan and health insurance benefit mandate legislation. SB 125 (Hernandez), Chapter 9, Statutes of 2015, added an impact assessment on essential health benefits, and legislation that impacts health insurance benefit designs, cost-sharing, premiums, and other health insurance topics to CHBRP's purview. CHBRP reviewed this bill and included the following impact estimates in their analysis:

1) *Premium & enrollee out-of-pocket increases.* Premiums paid by employers and enrollees would increase upon enaction of this bill by an estimated $148 million. Individual annual premium impacts range from $1.49 to $10.69 depending on market segment. The average annual enrollee premium impact for users is $1.90 for large-group, $3.80 for small-group, $10.69 for individual market, and $1.49 for California Public Employees' Retirement System (CalPERS) enrollees. This premium increase applies to all enrollees regardless of whether they use the new benefit. Annual expenses for those using drugs subject to this bill, including cost sharing and noncovered expenses, would increase by between $900 and $1,200. Over time, utilization of FDA-approved drugs for rare diseases is likely to increase as new drugs

are developed and receive FDA approval. These factors would contribute toward increases in premiums.

2) *Utilization Management (UM) and access to care.* CHBRP found there is not enough research on the impact of UM on access to rare-disease drugs. Based on existing literature and discussion with content experts, CHBRP determined that PA is typically the only type of UM used when reviewing access to coverage for FDA-approved drugs for rare-diseases. In studies of non-rare diseases, CHBRP found some evidence that PA results in delays for initiation of prescription drug treatments. CHBRP found that PA leads to a 60-day delay in access to all new prescriptions for users, i.e., individuals with rare diseases starting an FDA-approved drug. The 60-day delay estimate reflects clinical expert opinion from a specialist in rare metabolic diseases with extensive experience managing UM requirements for this patient population. Unlike other studies reviewed, which examined UM delays in more common conditions over shorter timeframes, rare disease PA processes are typically more burdensome, often requiring detailed diagnostic documentation, genetic testing results, and specialist attestation, justifying a longer timeline than observed for other treatments.

3) *Public health impacts.* CHRBP determined that this bill would produce no measurable public health impact at the population level. However, this bill could yield health and quality-of-life improvements at the person-level, such as faster access to medications, potential reductions in unnecessary health care utilization while awaiting PA for medications, and reduced stress and administrative burden for patients, their families, and their clinicians by removing PA requirements.

UM and UR. UM and UR are processes used by health plans to evaluate and manage the use of health care services. UR can occur prospectively, retrospectively, or concurrently and a plan can approve, modify, delay or deny in whole or in part a request based on its medical necessity. PA is a UR technique used by health plans that requires patients to obtain approval of a service or medication before care is provided. PA is intended to allow plans to evaluate whether care that has been prescribed is medically necessary for purposes of coverage. PA is a type of UM tool that's used by health plans, along with others such as concurrent review and step therapy, to control costs, limit unnecessary care, and evaluate safety and appropriateness of a service.

Growing consumer premiums and affordability concerns. Over the last two decades, significant federal policy changes have reshaped the health insurance landscape in California, expanding coverage, increasing affordability, and strengthening consumer protections for millions of residents. These policies drove historic reductions in the uninsured rate and provided greater stability for families, providers, and health systems across the state. These gains, however, are under threat as the expiration and rollback of key federal supports, combined with broader economic uncertainty and rising health care costs, risk reversing hard-won progress and increasing the number of Californians who are struggling to access affordable health care. According to the California Health Care Foundation 2026 Health Policy Survey (CHCF Survey), half of Californians (51%) reported that their health care expenses have increased faster than their incomes, and a vast majority (71%) are experiencing financial strain due to health care costs. About 6 in 10 Californians overall (59%), and 70% of Californians with low incomes, say they skipped or postponed care due to cost in the past year. Nearly half of Californians (47%) say it is "very" or "somewhat" difficult to afford health care.

Covered California. Covered California is the state's ACA marketplace where small-businesses and individuals can directly purchase coverage. Over 90% of Covered California enrollees receive some combination of state and federal subsidies to afford their premiums. However, the expiration of federal enhanced premium tax credits at the end of 2025 is creating stark affordability concerns. Covered California estimates that about 1.7 million Californians will see significant increases to their costs in 2026; on average, enrollees will notice 97% increases to their monthly health insurance premiums. As of February, Covered California estimated a 3% decrease in enrollment overall, with a 32% decrease in new enrollments compared to 2025. One-third of enrollees are opting for lower-cost Bronze plans, compared to 25% in 2025, and 75% of renewals who switched plans downgraded to Bronze-level coverage. About 14% of previous enrollees cancelled their plans, and for those making over 400% of the federal poverty level (FPL), policy termination rates are double what they were in 2025 (22% up from 11%). CHBRP's analysis showed this bill has the highest premium impacts in the Covered California individual and small-group markets.

Employer coverage. For those on employer-based individual and family plans, the California Health Benefits Survey found that the average total premium for family coverage in California has increased by 24% since 2022 – rapidly outpacing the national rates of inflation (12%) and wages (14%). This continues a 20-year trend: according to the UC Labor Center, family health care premiums for private-sector workers have grown by 129% since 2005, faster than the state's median household income (94%) and the inflation rate (69%). Because health insurance is part of an employee's total compensation plan, higher premiums cut into employee wage increases and other benefits.

Office of Health Care Affordability (OHCA) cost targets. OHCA was established in 2022 in response to widespread cost-related access challenges across California. OHCA collects, analyzes, and publicly reports data on total health care expenditures and enforces spending targets. OHCA's spending targets are intended to reduce excess spending and slow health care spending growth. In April of 2024, OHCA approved a statewide cost growth target of 3.5% starting in 2025 and phasing down to 3% by 2029. Health care entities, including health plans and insurers, are subject to the statewide spending target and are subject to progressive enforcement if the entity's costs exceed the target. Some entities have raised concerns that new legislative insurance mandates will make it difficult for them to meet the established cost growth target.

Current law does not explicitly require OHCA to adjust the cost growth targets based on changes to state policy, such as insurance mandates, that may increase spending. However, it does require OHCA to consider state benefit mandates in its development and enforcement of cost growth targets. Specifically, when establishing cost growth target methodology, OHCA is required to review relevant state policy changes impacting covered benefits, provider reimbursement, and costs, among other factors. In addition, in enforcing cost growth targets, OHCA is required to consider factors that contribute to spending in excess of the applicable target, and the extent to which each entity has control over the applicable components of its cost target.

According to the Author
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 PA from their health plan before they can start the one [federal Food and Drug Administration] FDA-approved drug that can slow or stop their condition. The author states that

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. The author continues that this bill removes these barriers by prohibiting PA, step therapy, and other UR for FDA-approved medications used to treat rare diseases, unless there is a generic or biosimilar alternative, thereby restoring treatment decisions to patients and their doctors. The author concludes that 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.

Arguments in Support
The California Chronic Care Coalition (CCCC) is sponsoring this bill, stating that many rare disease patients, especially children, experience years-long "diagnostic odysseys," seeing an average of 17 providers over more than six years before receiving an accurate diagnosis. CCCC continues that during those years alone, avoidable medical and productivity costs attributable to delayed diagnosis range from approximately $86,000 to $517,000 per patient. CCCC notes that when a rare disease is finally identified and an FDA-approved therapy exists, UM protocols that delay or deny access effectively extend this costly odyssey at the very point when patients are poised to benefit from appropriate treatment. CCCC argues that economic evidence strongly supports moving cost control "upstream" by ensuring timely access to appropriate treatment for rare disease patients rather than relying on downstream spending from preventable complications. CCCC cites a national study of 379 prevalent rare diseases that estimated the total economic burden at $997 billion annually, including $449 billion in direct medical costs, $437 billion in productivity losses, and substantial non-medical and uncovered costs. CCCC states that on a per-patient basis, the average annual economic burden for a person with a rare disease is roughly $266,000—10 times higher than the $26,000 per-patient burden associated with common diseases. CCCC argues that direct medical costs alone are three to five times higher for rare disease patients than for the general population, with hospital inpatient care and outpatient visits accounting for nearly half of those costs. CCCC continues that California's health policy framework emphasizes equity, quality, and measurable reductions in health disparities. CCCC argues that rare disease patients—especially children, communities of color, rural residents, non-English speakers, and families with limited resources—face disproportionate challenges navigating PA and step therapy appeals, compounding the inequities they already experience. CCCC concludes that by eliminating these barriers for a narrowly defined set of FDA-approved rare disease treatments, this bill advances California's equity goals and ensures that access is driven by clinical need rather than by a family's capacity to navigate insurance bureaucracy.

Arguments in Opposition
The California Association of Health Plans (CAHP) and Association of California Life and Health Insurance Companies (ACLHIC) are strongly opposed to any legislation that will increase premiums for Californians – especially at a time when health care affordability remains a critical concern. CAHP and ACLHIC urge members to vote no on this bill due to its astronomical impact to premiums. CAHP and ACLHIC note that UM is not an arbitrary practice, it ensures patients get the appropriate treatment, at the right time, for the most affordable price. CAHP and ACLHIC continue that this bill seeks to remove *all* utilization management practices for drugs used to treat rare diseases – which due to their complex formulation to target small populations, range in costs between hundreds of thousands of dollars to millions of dollars. CAHP and ACLHIC state that under this bill plans would have to offer blanket coverage for all new drugs used to treat rare diseases that enter the market (regardless of their efficacy or cost) and be

restricted in their abilities to manage formularies and provide appropriate coverage of high-priced drugs. CAHP and ACLHIC appreciate the provision on biosimilars, but state it is important to note that because these conditions are rare, it's likely that many of them are only treated by a biologic and do not have a biosimilar available. CAHP and ACLHIC continue that the legislature has spent the past year discussing policies to address the rising cost of healthcare – with a specific focus on health care premiums. CAHP and ACLHIC conclude by reminding the legislature that mandates have a direct correlation to premium increases for Californians and urge careful and consistent consideration of this individual proposal's impact and the cumulative impact of healthcare mandates.

FISCAL COMMENTS

According to the Assembly Committee on Appropriations:

1) CHBRP estimates premiums for health plans regulated by the Department of Managed Health Care (DMHC) and offered in CalPERS would increase by $7.36 million per year, of which the state's share is about $3.4 million (General Fund). Premiums would also rise for Department of Insurance (CDI)-regulated health insurance policies, the state's share of which would likely be in the low millions of dollars (General Fund).

2) The Legislative Analyst's Office recently warned of General Fund structural deficits of around $35 billion per year in fiscal year (FY) 2027-28 and ongoing.

3) CDI estimates costs of $12,000 in FY 2026-27, $26,000 in FY 2027-28, and $3,000 in FY 2028-29 and ongoing (Insurance Fund).

4) DMHC anticipates minor and absorbable costs.

5) CHBRP estimates this bill will increase total premiums for all payers by $147.8 million, including $88.7 million for employers, $25.2 million for employees in employer-sponsored insurance, and $26.6 million for individually purchased insurance.

VOTES

ASM HEALTH: 15-0-1
YES: Bonta, Addis, Aguiar-Curry, Ahrens, Caloza, Carrillo, Mark González, Johnson, Patel, Patterson, Rogers, Sanchez, Schiavo, Sharp-Collins, Stefani
ABS, ABST OR NV: Chen

ASM APPROPRIATIONS: 14-0-1
YES: Wicks, Hoover, Aguiar-Curry, Calderon, Caloza, Dixon, Fong, Mark González, Krell, Pacheco, Pellerin, Sharp-Collins, Solache, Ta
ABS, ABST OR NV: Tangipa

UPDATED

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