FAMILIESUSA
THE VOICE FOR HEALTH CARE CONSUMERS

April 2, 2026

Senate Committee on Health and Human Services
Colorado State Senate
200 E Colfax Ave
Denver, CO 80203

RE: CO SB26-140

Dear Chair Mullica, Vice Chair Jodeh, and Senators of the Health and Human Services Committee:

Thank you for the opportunity to provide testimony for today's hearing. On behalf of Families USA, a national, nonpartisan voice for health care consumers, we urge the Committee to reject SB26-140 and any legislation that would undermine Colorado's ability to secure lower prescription drug prices for its residents.

For more than 40 years, Families USA has worked toward a vision of a nation where the best health care is equally accessible and affordable to all. As part of that mission, we work closely with our partners in Colorado and other states across the country to support innovative policies that drive down health care costs, establish critical consumer protections, and improve health for everyone. Unfortunately, the bill under consideration before the Committee today runs counter to those goals. At a time when families are struggling with rising health care costs, SB26-140 would significantly weaken Colorado's ability to lower drug prices for its residents.

At its core, SB26-140 would undermine two of the most effective tools Colorado has to lower drug costs: the Prescription Drug Affordability Board (PDAB) and its authority to establish upper payment limits (UPLs). The bill would carve out sweeping exemptions that would shield some of the highest cost drugs from any affordability review or pricing actions – exemptions that go far beyond those included in federal law. Big drug companies backing this model of drug exemption legislation around the country employ misleading messaging to generate fear in families and lawmakers alike, making false claims that these exemptions are necessary to protect patient access to drugs. We urge Colorado lawmakers to reject these bad faith efforts to dismantle the meaningful drug pricing reforms that Colorado has rightfully championed for its residents.

High Drug Prices in Colorado and Across the Country

With millions of Americans increasingly concerned about the cost of basic needs, including skyrocketing health insurance costs, the need for tools to rein in the cost of health care is more urgent than ever.[1] Rising prescription drug costs remain a major driver of unaffordable health care both nationally and here in Colorado.[2] Between 2000 and 2022, the United States (US) per capita prescription drug spending increased from $432 to $1,217, a nearly three-fold increase.[3] In 2024 alone, the US spent $467 billion on prescription drugs, accounting for nearly 10% of total US health care spending.[4] This is a particularly acute problem in Colorado. According to Colorado's All Payer Claims Database, the state spent more than $6 billion on prescription drugs in 2023, representing more than 20% of the state's total health spending that year.[5]

These high costs have a ripple effect far beyond what people pay the pharmacy counter – decades of data show prices for hospital services and prescription drugs continue to be the leading drivers of high and rising health insurance premiums for both people who get coverage through their employers and people who purchase insurance in the Affordable Care Act (ACA) marketplaces.[6] In fact, the majority of 2026 insurance rate filings highlight the impact of high costs for specialty drugs and biologics as leading drivers of rising health insurance premiums.[7,8]

That's why Colorado's role as a national leader in the fight against high and rising health care prices is so important. It was the first state to implement an upper payment limit, and the second to establish a PDAB – two of the most promising and effective policy tools available to states to lower prescription drug prices.[9] These tools are particularly powerful when paired with federal reforms like the Medicare Drug Price Negotiation Program. Taken together, these recent advancements will ensure that Coloradans of all ages, enrolled in public and private insurance plans alike, can benefit from reasonable limits on the cost of lifesaving drugs.

Yet SB26-140 would undermine this progress by carving out a broad category of drugs from review, weakening the state's ability to deliver lower health care costs to patients and consumers right when they need it most.

SB26-140 Creates Sweeping Exemptions that Go Beyond Federal Law

If enacted, SB26-140 would prohibit Colorado's PDAB from conducting affordability reviews or establishing UPLs for *any* drug designated for a rare disease, including the approximately 20% of orphan drugs that are also approved to treat common diseases.[10] In other words,

SB26-140 would essentially shield an entire category of blockbuster drugs from any pricing oversight at the state level, regardless of how widely a drug is used or how high its prices are. This legislation is significantly more restrictive than federal policy, including changes made to the Medicare Drug Price Negotiation Program by Congress in July 2025 to create exemptions for certain orphan drugs and delays in eligibility for other drugs that later receive a non-rare indication.[11]

Importantly, even these more narrow exemptions on the federal level have already been shown to increase health care costs. The Congressional Budget Office (CBO) estimated that these federal changes will increase Medicare spending by at least $8.8 billion over 10 years.[12] This illustrates how even a targeted carve-out from drug pricing oversight has a major impact on overall health care affordability. For example, take the cancer drug Venclexta, which is now excluded from Medicare negotiation because it is approved for two rare conditions.[13] In 2023, it was used by more than 20,0000 Medicare enrollees, costing the program $826 million.[14] This is spending that is now unchecked and uncontrolled, leaving taxpayers to foot the bill and directly raising costs for patients who are relying on that medication for their cancer care.

As SB26-140 goes well beyond the more targeted federal exemption, the impact would be even more profound for Coloradans. By categorically excluding *all* drugs with *any* rare disease designation, the bill fundamentally undermines Colorado's ability to establish fair, rational drug prices for people dealing with a wide variety of health conditions, both rare and commonly experienced. And it will directly lead to higher health care costs for all Coloradans.

Federal Orphan Drug Framework: Generous Incentives Already in Place to Support Innovation

To the extent that big drug companies have been successful in securing exemptions from pricing efforts, they have relied heavily on generating misinformation about the nature and use of orphan drugs. Under federal law, "orphan drug" is a classification for drugs that treat small populations of people with rare diseases or conditions, and they can provide a lifeline for people with very limited treatment options.[15] Yet, despite orphan drugs being commonly thought of as narrowly used and highly specialized drugs, they often are used by millions of patients because many orphan drugs have also been approved by the Food and Drug Administration (FDA) for nonorphan indications to treat common diseases. Allowing them to generate billions in revenue.[16] In fact, orphan drugs are some of the most expensive drugs on the market: some 25 times more than non-orphan drugs.[17] In 2021, the average cost for an orphan drug was $218,871, compared to only $12,798 for a non-orphan drug.[18]

These expensive drugs are also quickly becoming a larger share of the drug market. Food and Drug Administration (FDA) approvals of orphan drugs have risen rapidly over the past two decades. Between 1998 and 2023, orphan drug approvals rose from 10% of all drug approvals to a whopping 43% of new drugs.[19] This growth is driven in large part by the fact that many orphan drugs can also be used for other indications to treat non-rare diseases.[20] As a result, these drugs are often highly profitable. Among the top 200 selling branded drugs globally, 73 were orphan drugs, and most generated over $1 billion in annual sales each.[21]

These revenues are built on top of substantial federal support. Without question, people with rare diseases and their families need investment to develop new therapies that give hope to those with limited or no treatment options. That's why the federal government spends billions of dollars every year on research to help develop new and innovative therapies.[22] In fact, taxpayer-funded research supported every new drug – every orphan drug – that was approved between 2010 and 2019.[23] And those are not the only government-sponsored motivators for drug companies to develop these therapies.

For decades, drug companies have received significant incentives for investment in orphan drug research and development established through the Orphan Drug Act of 1983,[24] including:

- Seven years of exclusivity to protect them from generic competition.[25]
- Expedited approval pathways such as Fast Track Designation, Breakthrough Therapy Designation, Accelerated Approval Program, and Priority Review Designation—designed to help get new medications that might meet unmet medical need, or offer significant improvements to treatment options, onto the market faster.[26]
- 25% tax credits on qualified clinical trials, which makes it more affordable for drug companies to develop orphan drugs.[27]

Taken together, these incentives ensure that drug companies receive significant financial support from the federal government before an orphan drug even goes onto the market. And when they do finally go to market, these drugs often bring in record profits.[28] Additional exemptions from pricing regulations are not only unnecessary, they will actually harm the very patients who need affordable access to these drugs.

A Broader Strategy to Weaken Drug Pricing Reforms

Make no mistake: efforts by drug companies to secure exemptions for narrow classes of drugs are not isolated, nor are they merely policy tweaks - they are part of a broader, deliberate strategy to weaken drug pricing reforms piece by piece. Rather than pursuing a

full repeal of reasonable pricing limitations that would draw public scrutiny, the industry is advancing incremental carve-outs designed to quietly erode consumer protections and return to a business model that enabled unchecked price gouging of both government budgets and patient pocketbooks. Each exemption may appear limited, but together they systematically narrow the scope and effectiveness of meaningful policy reforms.

We've seen this strategy play out at the federal level, as recently as H.R. 1, the "One Big Beautiful Bill Act," which expanded exemptions for orphan drugs under the Medicare Drug Price Negotiation Program,[29] undermining one of the most effective tools available to lower prescription drug costs nationwide.

SB26-140 is another clear example of this playbook in action. Colorado lawmakers should view this latest attempt to create backdoor loopholes for high-cost drugs with appropriate skepticism. This predatory, profiteering behavior from drug companies was the very reason the state created PDAB and UPL authority in the first place.[30]

For drug pricing reforms to deliver meaningful relief to families, all categories of drugs must remain on the table for oversight and appropriate pricing review. Allowing continued carve-outs or exemptions invites a system where drug companies effectively choose which of their products are subject to competition and which remain insulated from it. Left unchecked, this approach will hollow out existing protections, undermine Colorado's landmark reforms, and hand pricing power back to an industry that has repeatedly demonstrated it cannot be trusted to self-regulate.

Protect Patient Access to Affordable Prescription Drugs

Big drug companies charge exorbitantly high prices for their drugs even though they have benefited from significant financial incentives to research and develop them. And the people who rely on those drugs to treat both rare and commonly experienced health conditions — along with anyone who accesses our health care system — are paying the price. Colorado has demonstrated its willingness to put the needs of Colorado families ahead of the interests of drugmakers seeking higher and higher profits. It is time to show that leadership once again. Senators of this committee should oppose drug companies' continued efforts to circumvent Colorado's existing reforms, and that includes opposing SB26-140.

Thank you for the opportunity to testify, and for your time and commitment to making health care more affordable and accessible for Coloradans across the state.

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