We support SB26-140 because of our compassion for rare disease patients. We helped care for our granddaughter, Maya, since she was born. Maya was born with a rare disease, cystic fibrosis (CF) which affects her lung and pancreas functions. Her life expectancy as well as her quality of life were significantly hindered due to lung infections, digestive and breathing issues and hospitalizations caused by CF. Maya endured rigorous daily treatments including two 30-minute sessions of chest percussions. She also did daily nebulizer treatments to slow the decline of her lung function caused by thick mucus formation because of CF.

A few years ago, Maya had the opportunity to participate in a drug trial. A new drug called Trikafta was being tested to negate some of the effects of CF. This drug has literally been life saving for Maya. Praise God and the hard work and dedication of all the people who helped to make the drug available for our granddaughter.

Senate bill 21-175 established the Colorado Prescription Drug Affordability Board (PDAB). The bill states that for the health of Colorado residents, it is imperative that Colorado take measures to reduce excessive prescription drug costs and protect Colorado residents from the excessive costs of prescription drugs.

Trikafta, Maya's life-saving drug, was the first to be reviewed by PDAB. We refer to Trikafta as an orphan drug because it is the only drug available to treat her condition. The PDAB committee considered placing an upper payment limit on Trikafta. We were very aware that the manufacturer could decide not to make Trikafta available in Colorado should the limit be placed. Without this medication, Maya would once again have difficulty breathing, frequent lung and other infections, hospitalizations, eventually could need a lung transplant and face an early death. The ironic thing is that the bill states it is (1) for the health of Colorado residents and (2) to protect Colorado resident from the excessive costs of prescription drugs. Had the PDAB committee placed an upper payment limit on Trikafta, it would have failed in fulfilling its two main goals. Without access to Trikafta Maya would once again be caught in a downward spiral which clearly does not support her health. Also, there would be no cost savings for her or anyone else. The dollar cost associated with untreated CF is enormous. And then there is quality of life and her opportunity to be a productive citizen. Prior to Trikafta and because of the cycle of illnesses, Maya was unable to stay in school for any length of time. She is currently in college and is a biology major with a bright future. Until the impact of upper payment limits is better understood, please protect our access to life-saving options.

Lyle and Connie Reinhardt
7549 S Quatar Way
Aurora, CO 80016

SMALL BUSINESS MAJORITY

March 27, 2026

Chair Kyle Mullica and members of the committee
Colorado Senate Health & Human Services Committee
200 E Colfax, RM 346
Denver, CO 80203

RE: Comments in opposition to SB26-140 Exempt Drugs from Prescription Drug Affordability Board Reviews

As a representative of Colorado's more than 730,000 small businesses, Small Business Majority urges you to oppose SB26-140. This legislation would prevent Colorado's Prescription Drug Affordability Board (PDAB) from reviewing the cost of hundreds of commonly prescribed medications that Coloradans struggle to afford every day.

Access to affordable, quality healthcare is crucial to small businesses' ability to compete with large corporations for talented employees, in addition to ensuring entrepreneurs and their employees get the care they need. Health coverage is most small businesses' largest expense outside of payroll. That's why it's worrisome that our research found small businesses are struggling amid rising healthcare costs, with 76% saying that prescription drug prices in America are too high.[1] It's not surprising that 90% of small business owners support proposals that would bring down the cost of prescription drugs.[2]

In response, Colorado's policymakers created a PDAB that is now the leader in addressing skyrocketing prescription drug costs. For instance, Colorado's PDAB set the first-in-the-nation Upper Payment Limit (UPL) on Enbrel, which is projected to save Coloradans approximately $38 million a year.[3] That's why it's concerning that SB26-140 is trying to reverse this success, which would drive up costs for Colorado small business owners and their employees.

This legislation would take away the Board's authority to review the affordability of some of the most expensive prescription medications and prevent Colorado's PDAB from lowering the cost of these medications. Patients with rare diseases are among the most harmed by out-of-control drug costs. That's why the pharmaceutical industry is focused on exempting medications that treat rare diseases because they are extremely profitable and face no market competition.

SB26-140 is part of the pharmaceutical industry's national strategy to make it impossible for states to bring down the cost of prescription medications. We urge you to oppose this legislation to protect Colorado PDAB's work to lower costs for small business owners and their employees.

Sincerely,

Awesta Sarkash
Vice President, State Policy & Advocacy
Small Business Majority

[1] "Opinion poll: Small businesses struggling with rising healthcare costs, support bipartisan policy solutions." Small Business Majority. February 21, 2024. https://smallbusinessmajority.org/our-research/healthcare/small-businesses-struggling-rising-healthcare-costs-support-bipartisan-policy-solutions

[2] "Small businesses struggling to access healthcare during COVID-19 pandemic." Small Business Majority. March 31, 2021. https://smallbusinessmajority.org/our-research/healthcare/small-businesses-struggling-access-healthcare-during-covid-19-pandemic

[3] "Consumer advocates praise Prescription Drug Affordability Board's decision to set first-in-nation Upper Payment Limit on the expensive drug Enbrel." Colorado Consumer Health Initiative. October 3, 2025. https://cohealthinitiative.org/media-releases/consumer-advocates-praise-prescription-drug-affordability-boards-decision-to-set-first-in-nation-upper-payment-limit-on-the-expensive-drug-enbrel/

To: Senator Kyle Mullica, Colorado Senate Health & Human Services Committee Chair
Senator Iman Jodeh, Colorado Senate Health & Human Services Committee Vice Chair
Members, Colorado Senate Health & Human Services Committee

RE: Support for SB26-140 Exempting Rare Disease Drugs from Prescription Drug Affordability Board Reviews

Colorado Organizations & Individuals Responding to HIV/AIDS (CORA) appreciates the opportunity to submit testimony regarding SB26-140, which would exempt medications that treat rare diseases and those derived from whole blood or plasma from review by the state Prescription Drug Affordability Review Board (PDAB). CORA is a statewide coalition representing the more than 15,800 Coloradans living with HIV, the countless others with reasons for HIV prevention, and the organizations that serve them. Our organization supports SB 140 and we urge the committee to vote “yes” to protect access to care for vulnerable Coloradans.

HIV treatment and prevention has greatly improved since the early days of the epidemic. Today’s medications have fewer side effects and allow people living with HIV to enjoy long, healthy lives. In addition, individuals can take highly effective medications to help stay HIV-negative. We appreciate the stated intent of the PDAB to increase transparency around the high cost of prescription drugs and to address this barrier to essential medications for people living with HIV and other chronic or complex medical conditions. However, our previous experience with the PDAB’s review process revealed numerous barriers to meaningful stakeholder engagement or proper consideration of potential unintended consequences to vulnerable Coloradans that may arise from imposing an upper payment limit (UPL).

For Coloradans with a rare disease, Coloradans living with HIV, or other Coloradans with chronic or complex health conditions, the risk that an upper payment limit will jeopardize access to critical medications is especially great. Since these individuals account for a small proportion of Coloradans taking prescription medications, and Colorado represents a considerably smaller market than more populous states like California or Texas, there are less incentives to prevent drug manufacturers from responding to a UPL on these medications by refusing to sell them in Colorado entirely. In fact, when the PDAB was reviewing Genvoya (an HIV treatment medication), that medication’s manufacturer (Gilead) explicitly would not rule out taking this action when questioned by CORA or other community members about the company’s plans should a UPL be adopted.

Upper payment limits could also negatively impact safety net providers that act as vital lifelines for many Coloradans and make these medications more affordable. Through the federal 340B drug pricing program, for instance, safety net providers reinvest the difference between market and discounted prices to stretch scarce resources and serve more vulnerable individuals. UPL constraints on reimbursement rates could reduce these savings, resulting in reduced access to

specialty care in rural or under-resourced communities and additional strain on Colorado's health care system. Though the PDAB is statutorily required to weigh these impacts during the affordability review process, the board has consistently struggled to adequately capture the necessary data or consult with safety-net providers.

It is also unclear whether a UPL will truly result in lower out-of-pocket medication costs for individuals since it doesn't address other points within the drug supply chain. Health plan benefit designs often play a significant role in determining what someone pays for a medication at the counter. Yet there is no requirement for insurers or pharmacy benefit managers (PBMs) to pass on savings to enrollees and copays or deductibles are not subject to upper payment limits. A UPL could, thus, result in inflated profits for private insurers without translating to greater affordability for Coloradans.

Furthermore, the PDAB review process suffers from statutory constraints that prevent the board from effectively engaging with impacted Coloradans and from accounting for unique characteristics of different medications or health conditions. Some of these challenges include the lack of a transparent, data driven method of estimating the impact of UPLs, the inability to monitor patient access to medication with UPLs, and challenges with the public input process. CORA was very engaged in the stakeholder process for Genvoya PDAB review, finding the focus groups and opportunity for patients to provide comments rigid, difficult to share "real life" stories and inequitable. Several of these challenges are highlighted in the 2023 Affordability Review Summary Report: Genvoya published February of 2024, Genvoya ultimately was not deemed unaffordable and the 800 patients still have access to this medication. Division of Insurance staff have acknowledged these flaws but shared that they are limited in their ability to reform the process by the existing statutes governing the board. We have grave concerns that by definition, those living with rare disease will have significantly small patient groups limiting their access and advocacy.

The Prescription Drug Affordability Advisory Council (PDAAC) has recognized these concerns and recommended that medications treating rare diseases be exempted from the PDAB review process, but the PDAB has yet to implement this change. SB 140 codifies this exemption and aligns Colorado with many other states (ex: Washington and Oregon) with similar boards. CORA shares the board's goal of improving access to medications for Coloradans, but upper payment limits are an overly broad policy tool and risk making it even more difficult for Coloradans living with a rare disease or other serious conditions to get the care they need. We join rare disease advocates in calling for a "Yes" vote on SB 140 to protect access to care for vulnerable Coloradans, and we look forward to working with the General Assembly in the future on additionally needed PDAB reforms. Thank you for your consideration and please don't hesitate to reach out with any questions

Barb Cardell, Co-Chair (barb@pwn-usa.org)

Matt Pagnotti, Co-Chair (matt.pagnotti@viventhealth.org)

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 Jenet, 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.

[1] Grace Sparks, Lunna Lopes, Alex Montero, et al, "Americans' Challenges with Health Care Costs," KFF, January 29, 2026, https://www.kff.org/health-costs/americans-challenges-with-health-care-costs/; Lydia Saad, "Healthcare Reclaims Top Spot Among U.S. Domestic Worries," Gallup, March 31, 2026, https://news.gallup.com/poll/707732/healthcare-reclaims-top-spot-among-domestic-worries.aspx.
[2] Benjamin N. Rome, Alexander C. Egilman, and Aaron S. Kesselheim, "Trends in Prescription Drug Launch Prices, 2008- 2021," JAMA 327, no. 21 (2022): 2145–2147, https://jamanetwork.com/journals/jama/article-abstract/2792986.
[3] "National spending on services and prescriptions," Peterson-KFF Health System Tracker, https://www.healthsystemtracker.org/indicator/spending/national-spending-services/.
[4] "National Health Expenditures 2024 Highlights," Centers for Medicare and Medicaid Services, January 14, 2026, https://www.cms.gov/files/document/highlights.pdf.
[5] "Prescription Drug Rebates," Center for Improving Value in Health Care, https://civhc.org/get-data/public-data/focus-areas/prescription-drug-rebates/; "Community Dashboard," Center for Improving Value in Health Care," https://civhc.org/get-data/public-data/community-dashboard/.
[6] Sophia Tripoli and Alicia Camaliche, "Why Health Insurance Premiums Continue to Skyrocket- and What Congress Can Do About It," Families USA, November 2025, https://familiesusa.org/wp-content/uploads/2025/11/Why-Health-Insurance-Premiums-Continue-to-Skyrocket.pdf.
[7] Jared Ortaliza, Matt McGough, Kaitlyn Vu, Imani Telesford, Shameek Rakshit, Emma Wager, Lynne Cotter, and Cynthia Cox, "How much and why are ACA Marketplace premiums going up in 2026," Peterson-KFF Health System Tracker, August 6, 2025, https://www.healthsystemtracker.org/brief/how-much-and-why-aca-marketplace-premiums-are-going-up-in-2026/; Jason Karcher et al., "Drivers of 2026 Premium Changes," American Academy of Actuaries, July 2025, https://www.actuary.org/wp-content/uploads/2025/07/brief-Drivers-2026-Premium.pdf.
[8] Families USA's review of filings publicly posted on HealthCare.gov (https://ratereview.healthcare.gov/) and on state insurance department websites, July and August 2025.
[9] "Consumer advocates praise Prescription Drug Affordability Board's decision to set first-in-nation Upper Payment Limit on the expensive drug Enbrel," Colorado Consumer Health Initiative, October 3, 2025, https://cohealthinitiative.org/media-releases/consumer-advocates-praise-prescription-drug-affordability-boards-decision-to-set-first-in-nation-upper-payment-limit-on-the-expensive-drug-enbrel/; "State Policies for Lowering Drug Prices Policy Brief," Arnold Ventures, April 2, 2025, https://www.arnoldventures.org/resources/state-policies-for-lowering-drug-prices-policy-brief.
[10] "SB26-140," 75th Colorado General Assembly, https://leg.colorado.gov/bills/SB26-140; Kathleen L. Miller and Michael Lanthier, "Orphan Drug Label Expansions: Analysis of Subsequent Rare and Common Indication Approvals," Health Affairs Vol. 43, No. 1, January 24, https://doi.org/10.1377/hlthaff.2023.00219.
[11] "H.R. 1 - An act to provide for reconciliation pursuant to title II of H. Con. Res. 14." 119th Congress, https://www.congress.gov/bill/119th-congress/house-bill/1/text.
[12] Phillip L. Swagel, "Revised Estimate of Changes Under the 2025 Reconciliation Act for Exemptions From Medicare Price Negotiations for Orphan Drugs," Congressional Budget Office, October 20, 2025, https://www.cbo.gov/publication/61818
[13] "Search Orphan Drug Designations and Approvals," U.S. Food and Drug Administration, https://www.accessdata.fda.gov/scripts/opdlisting/oopd/listResult.cfm; "FDA Approves Venetoclax for CLL and SLL," U.S. Food and Drug Administration, May 15, 2019, https://www.fda.gov/drugs/resources-information-approved-drugs/fda-approves-venetoclax-cll-and-sll.
[14] Juliette Cubanski and Tricia Neuman, "People with Medicare Will Face Higher Costs for Some Orphan Drugs Due to Changes in the New Tax and Budget Law," KFF, October 20, 2025, https://www.kff.org/medicare/people-with-medicare-will-face-higher-costs-for-some-orphan-drugs-due-to-changes-in-the-new-tax-and-budget-law/.
[15] "Definition of orphan drug designation," National Cancer Institute, https://www.cancer.gov/publications/dictionaries/cancer-terms/def/orphan-drug-designation.

[16] "Orphan Drug Label Expansions: Analysis of Subsequent Rare and Common Indication Approvals," Health Affairs Vol. 43, No. 1, January 24, https://doi.org/10.1377/hlthaff.2023.00219.
[17] "New Study: Big Pharma Price-Gouging Medications For Rare Diseases At Staggering Rate," the Campaign for Sustainable Rx Pricing, September 11, 2019, https://www.csrxp.org/new-study-big-pharma-price-gouging-medications-for-rare-diseases-at-staggering-rate/.
[18] Hanah Althobaiti, Enrique Seoane-Vazquez, Lawrence M. Brown, Marc L. Fleming, and Rosa Rodriguez-Monguio, "Disentangling the Cost of Orphan Drugs Marketed in the United States," *Healthcare* 2023 11 (4), https://doi.org/10.3390/healthcare11040558.
[19] Sean Tu, "WVU research shows how much pharmaceutical companies are capitalizing on rare drug incentives," WVU Today, June 12, 2023, https://wvutoday.wvu.edu/stories/2023/06/12/wvu-research-shows-how-much-pharmaceutical-companies-arecapitalizing-on-rare-drug-incentives.
[20] Kathleen L. Miller and Michael Lanthier, "Orphan Drug Label Expansions: Analysis of Subsequent Rare and Common Indication Approvals," Health Affairs 43, no. 1 (January 2024), https://doi.org/10.1377/hlthaff.2023.00219; Mike McCaughan, "Pricing Orphan Drugs," Health Affairs, July 21, 2017, https://www.healthaffairs.org/do/10.1377/hpb20170721.588081/full/.
[21] Kathleen L. Miller and Michael Lanthier, "Orphan Drug Label Expansions: Analysis of Subsequent Rare and Common Indication Approvals," Health Affairs, January 2024, https://www.healthaffairs.org/doi/pdf/10.1377/hlthaff.2023.00219.
[22] Ekaterina Cleary, Matthew J. Jackson, and Fred Ledley, "Government as the First Investor in Biopharmaceutical Innovation: Evidence from New Drug Approvals 2010-2019," Institute for New Economic Thinking Working Paper Series No. 133, November 18, 2020, https://doi.org/10.36687/inetwp133.
[23] Ibid
[24] Mike McCaughan, "Pricing Orphan Drugs," Health Affairs, July 21, 2017, https://www.healthaffairs.org/do/10.1377/hpb20170721.588081/full/.
[25] "Exclusivity and Generic Drugs: What Does It Mean?" U.S. Food and Drug Administration, accessed September 19, 2025, https://www.fda.gov/media/111069/download.
[26] Scott N. Freeman, "Expedited FDA Programs: Accelerating Orphan Drug Access," FDA Orphan Drug Regulation, LinkedIn, https://www.linkedin.com/pulse/expedited-fda-programs-accelerating-orphan-drug-scott-n-freeman-phd/.
[27] Alexis-Danielle Roberts and Roopma Wadhwa, "Orphan Drug Approval Laws," StatPearls, June 5, 2023, https://www.ncbi.nlm.nih.gov/books/NBK572052/; Julie Kagan, "Orphan Drug Credit: What It Is, How It Works," Investopedia, updated July 31, 2021, https://www.investopedia.com/terms/o/orphan-drug-credit.asp.
[28] M. Ian Phillips, "Big Pharma's New Model in Orphan Drugs and Rare Diseases," Expert Opinion on Orphan Drugs 1, no. 1 (December 17, 2012): 1–3, https://doi.org/10.1517/21678707.2013.752128; AHIP, "How Big Pharma Makes Big Profits on Orphan Drugs," September 10, 2019, https://www.ahip.org/how-big-pharma-makes-big-profits-on-orphan-drugs.
[29] "Health Provisions in the 2025 Federal Budget Reconciliation Law," KFF, August 22, 2025, https://www.kff.org/medicaid/health-provisions-in-the-2025-federal-budget-reconciliation-law/.
[30] "SB21-175," 73th Colorado General Assembly, https://leg.colorado.gov/bills/sb21-175.

Immune Deficiency Foundation

Fostering a community empowered by advocacy, education, and research

April 2, 2026

The Honorable Kyle Mullica
Chair, Health and Human Services Committee
200 E Colfax RM 346
Denver, CO 80203

Re: Support for SB26-140 - Exempt Drugs from Prescription Drug Affordability Board Reviews

Dear Chair Mullica, Vice Chair Jodeh, and Honorable Committee Members,

On behalf of all people impacted by primary immunodeficiency (PI), the Immune Deficiency Foundation urges you to support SB26-140 to ensure access to life-sustaining medications derived from donated blood plasma for our rare disease community. Specifically, we urge you to support SB26-140 to exclude therapies derived from human blood plasma, which include immunoglobulin (Ig) products used to treat people with PI, from review by the Colorado Prescription Drug Affordability Board (PDAB).

The mission of the Immune Deficiency Foundation is to improve the diagnosis, treatment, and quality of life for every person affected by primary immunodeficiency (PI). PIs are a group of more than 550 rare, genetic, chronic conditions in which part of the body's immune system is missing or does not function correctly, leading to infection, cancer, allergy, autoimmunity, autoinflammation, or any combination. The National Institutes of Health estimates that approximately 500,000 individuals in the U.S. have a PI.

An effective treatment for many people living with PI is immunoglobulin (Ig) replacement therapy, which replaces the antibodies the body cannot produce sufficiently. Because Ig derives from human plasma, it cannot be produced without a continuous supply of source plasma — the liquid, cell-free component of blood — from donors. With a limited supply, a long and complex manufacturing process, and increased therapeutic uses, access to Ig and other plasma derived therapies is an ongoing issue for rare disease patients. We are concerned that the PDAB affordability review and establishment of an upper payment limit could negatively impact manufacturers' ability to produce enough Ig to meet the growing demand and that the PI community will not be able to access the therapies on which they rely.

There is precedence for excluding Ig and other plasma protein therapies from past federal policies. For example, intravenous immunoglobulin (IVIG) was excluded from the Medicare MFN innovation model proposed in 2020, noting that these products are at higher risk of shortage

due to their complex sourcing and production. Further, for the same reasons, plasma protein therapies were exempted from the Inflation Reduction Act's price negotiation provisions in 2022.

We urge you to support SB26-140 to exclude plasma-derived products from the PDAB's review. Thank you for your attention to this matter. If you have any questions, please contact me at mprentice@primaryimmune.org

Sincerely,

Matthew Prentice, MPH
Director of State Policy
Immune Deficiency Foundation
(443) 901-4579
mprentice@primaryimmune.org

April 1, 2026

Testimony of the Rare & Ready Coalition in Support of SB26-140

Dear Committee Chair and Members,

On behalf of the Rare & Ready Coalition, we respectfully urge your support for SB26-140, which would exempt rare disease and plasma-derived therapies from Prescription Drug Affordability Board (PDAB) review.

There are approximately 10,000 known rare diseases, but **only 5% have an FDA-approved therapy**. There are only **552 drugs and biologics** on the market having an orphan designation and **75% of those treat just a single rare disease**.[1] Unlike traditional medicines, orphan drugs serve extremely small patient populations and have limited clinical use, only **10%, about 60 drugs,** are approved for multiple indications.[2]

SB26-140 recognizes this reality. By exempting rare disease and plasma-derived therapies from PDAB review, the bill helps ensure that patients can maintain access to the only treatments designed for their conditions. For these patients — many of whom are children — these treatments are not optional; they are often the only available lifeline.

PDAB policies, while well-intentioned, can have serious unintended consequences for the rare disease community. These boards can restrict access to medications, deter future research and development, and weaken longstanding orphan drug protections. Most importantly, they can put patients at risk of losing access to the only therapies that sustain or extend their lives.

PDABs do not lower out-of-pocket costs at the pharmacy counter or reduce insurance premiums. Instead, they can create access barriers by limiting the ability of insurers and pharmacies to obtain therapies priced above state-imposed thresholds.

Other states, including Oregon and Washington, have already recognized these risks and taken action to exempt rare disease treatments from PDAB review. Colorado now has the opportunity to follow their lead and protect its most vulnerable patients.

For individuals living with rare diseases, access to treatment is essential to survival, quality of life, and hope for the future. **These therapies are not widely used, broadly interchangeable drugs—they are highly specialized treatments, often designed for one condition.** SB26-140 ensures that these patients are not unintentionally harmed by policies that were never designed for them.

Respectfully,
Rare & Ready Coalition

[1-2] "Orphan Drugs in the United States: An Examination of Patents and Orphan Drug Exclusivity," available at www.rarediseases.org/rareinsights

Senate Health & Human Services

04/02/2026

SB26-140 Exempt Drugs from Rx Drug Affordability Bd Reviews

Typed Text of Testimony Submitted

Name, Position, Representing	**Typed Text of Testimony**
Nicole Villas For Dravet Syndrome Foundation	Dear Senators, My name is Nicole Villas, and I am the mother of a 20 year old son with a severe, catastrophic,Â rare form of epilepsy called Dravet syndrome. He has frequent, prolonged seizures, the longestÂ being nearly 3 hours of constant convulsions, hypoxia, and requiring intubation. Dravet syndrome is genetic, although it is de novo meaning we, his parents, do not carry the mutation. I would be testifying in person for this bill if it were on any day except Thursday 4/2. Aiden suffers from seizures much of the day, has an Intellectual and Developmental Disability (IDD), has trouble speaking and walking, and functions at about a 3 yr old level. However, his access to a medication with Orphan Drug Designation during his prime developmental years, between 2008 and 2015, slowed his seizure progression significantly and prevented extensive hospitalizations and intubations. We credit this Orphan drug with saving his life and allowing him to surpass the 20% mortality rate from Sudden Unexpected Death in Epilepsy (SUDEP) and complications from prolonged seizures. Had the drug, stiripentol (Diacomit) been subject to PDAB, he likely would not have had access and could have easily been a mortality statistic.Â There are currently two genetic treatments in clinical trials for Dravet syndrome, and we are hopeful that they will help him attain near seizure-freedom and regain cognitive skills. If these treatments are capped by the PDAB, there is no chance families will be able to afford their high price tag. Similarly, it will discourage researchers from working on any such treatments for rare diseases, knowing the likelihood of patients being able to access them even if they pass the rigorous testing still required for rare diseases will be slim.Â I urge you to pass SB26-140, exempting rare treatments from the PDAB, and retaining life for people like my son who already benefited from an orphan drug and will hopefully benefit from another treatment in the next 10 years. Sincerely,

	NicoleÂ Mom to Aiden, 20, with Dravet syndrome. "Graduate" of one orphan drug, clinical trial participant in andÂ user of another, and likely candidate for a biologic soon.Â
Virginia Gebhart Against themself	I'm worried that this bill's intent is honorable, to assure patients that their medications will always be available to them in Colorado, but the effect of the bill will be harmful. I'm worried that Sen Marchman's constituents who live in fear that they will not be able to get their lifesaving medications have been subject to fear mongering by Big Pharma. The PDAB process has been very careful and deliberate. The process would not set price limits on orphan drugs or other drugs that have no equivalent or alternative for treatment of rare diseases. I'm worried that this bill affects more than orphan drugs and would allow Big Pharma to continue to charge whatever they want for other expensive drugs, besides orphan drugs. The PDAB process is a tiny check on the outrageously high prices we patients and taxpayers must pay for lifesaving medications. Let PDAB function so it can produce at least some savings for patients and taxpayers alike. Please vote no.

We support SB26-140 because of our compassion for rare disease patients. We helped care for our granddaughter, Maya, since she was born. Maya was born with a rare disease, cystic fibrosis (CF) which affects her lung and pancreas functions. Her life expectancy as well as her quality of life were significantly hindered due to lung infections, digestive and breathing issues and hospitalizations caused by CF. Maya endured rigorous daily treatments including two 30-minute sessions of chest percussions. She also did daily nebulizer treatments to slow the decline of her lung function caused by thick mucus formation because of CF.

A few years ago, Maya had the opportunity to participate in a drug trial. A new drug called Trikafta was being tested to negate some of the effects of CF. This drug has literally been life saving for Maya. Praise God and the hard work and dedication of all the people who helped to make the drug available for our granddaughter.

Senate bill 21-175 established the Colorado Prescription Drug Affordability Board (PDAB). The bill states that for the health of Colorado residents, it is imperative that Colorado take measures to reduce excessive prescription drug costs and protect Colorado residents from the excessive costs of prescription drugs.

Trikafta, Maya's life-saving drug, was the first to be reviewed by PDAB. We refer to Trikafta as an orphan drug because it is the only drug available to treat her condition. The PDAB committee considered placing an upper payment limit on Trikafta. We were very aware that the manufacturer could decide not to make Trikafta available in Colorado should the limit be placed. Without this medication, Maya would once again have difficulty breathing, frequent lung and other infections, hospitalizations, eventually could need a lung transplant and face an early death. The ironic thing is that the bill states it is (1) for the health of Colorado residents and (2) to protect Colorado resident from the excessive costs of prescription drugs. Had the PDAB committee placed an upper payment limit on Trikafta, it would have failed in fulfilling its two main goals. Without access to Trikafta Maya would once again be caught in a downward spiral which clearly does not support her health. Also, there would be no cost savings for her or anyone else. The dollar cost associated with untreated CF is enormous. And then there is quality of life and her opportunity to be a productive citizen. Prior to Trikafta and because of the cycle of illnesses, Maya was unable to stay in school for any length of time. She is currently in college and is a biology major with a bright future. Until the impact of upper payment limits is better understood, please protect our access to life-saving options.

Lyle and Connie Reinhardt
7549 S Quatar Way
Aurora, CO 80016

April 2, 2026 Hearing Before the Colorado General Assembly Senate Health & Human Services Committee: Written Testimony Regarding SB26-140

My name is Rachel Sachs and I am a Professor of Law at Washington University in St. Louis, where my research focuses on innovation and access to new healthcare technologies, primarily pharmaceuticals. I also serve as a secondary faculty member in Washington University's School of Public Health and a Faculty Co-Director of Washington University's Cordell Institute for Policy in Medicine and Law. Thank you for the opportunity to provide testimony regarding SB26-140. My testimony focuses on Section (1)(b) of the bill. All views I offer are my own.[1]

I. Orphan Drug Designations and Their Relationship to High-Cost Drugs

The Orphan Drug Act was enacted in 1983 with the goal of promoting innovation into drugs to treat rare diseases, primarily those affecting fewer than 200,000 Americans.[2] The law provided a range of benefits to pharmaceutical companies developing such products. A drug granted an orphan designation may qualify its manufacturer for tax credits and exemptions from marketing application fees, and if the drug is ultimately approved for the orphan indication, the manufacturer may receive seven years of market exclusivity protecting its approved product from competition for its rare disease use.[3] Before receiving these benefits, though, a drug manufacturer must receive an orphan drug "designation" for its product under 21 U.S.C. § 360bb. This designation is specific to the rare disease or condition at issue. Orphan designation is therefore a precursor to, but a distinct procedural stage from, FDA approval.

Rare disease drugs now "comprise a substantial proportion of the novel products reviewed and approved by FDA."[4] From 2018 through 2023, 52% of all novel drugs approved had an orphan designation.[5] Importantly, an orphan drug "may receive marketing approval for a single orphan indication, multiple orphan indications, or a combination of orphan and nonorphan indications."[6] Many products receiving orphan designations or approvals can be highly lucrative. A 2020 Department of Health and Human Services Office of Inspector General study of 40 high-expenditure Medicare Part B and Part D drugs found that 22 of those drugs (55%) had received at least one orphan designation and 20 (50%) had received marketing approval for at least one orphan indication.[7] (Eighteen products had no orphan designations.) United States sales alone exceeded $1 billion per drug in 2018 for 19 of the 22 orphan drugs, with global sales significantly increasing those figures.[8] The seven out of 40 (17.5%) products with only orphan indications were similarly highly lucrative. As one example, Revlimid earned $6.5 billion in U.S. drug sales in 2018 alone across its nine orphan indications.[9]

II. The Medicare Drug Price Negotiation Program

As initially enacted in the Inflation Reduction Act of 2022, the Medicare Drug Price Negotiation Program contained a narrow orphan drug exclusion. The 2022 version of the Negotiation Program orphan exclusion applied only to a "drug that is designated as a drug for only one rare disease or condition … and for which the only approved indication (or indications) is for such disease or condition."[10] The Centers for Medicare & Medicaid Services clarified that drugs that had been designated for multiple orphan indications did not qualify under this exclusion.[11] The text would also not have applied to products that had received approval for non-orphan indications (in addition to a single rare condition). Drugs like Humira (global sales $21.2 billion

in 2022)[12] and Keytruda (global sales $20.9 billion in 2022)[13], which have both orphan- and non-orphan approvals, would not have been excluded from negotiation on such grounds.

The 2025 reconciliation package expanded the Negotiation Program's orphan drug exemption not only to exclude drugs designated or approved for "one or more" rare diseases but also to, essentially, toll the time for determining when a drug would become eligible for negotiation by starting the eligibility clock "when FDA approved the first *non-orphan* indication, rather than when FDA approved the first indication, regardless of orphan status."[14] This change has delayed the selection of blockbuster drugs like Keytruda and Opdivo in the near term and has likely prevented the selection of other blockbuster drugs, such as Darzalex, even in future years. The Congressional Budget Office estimated that this expansion of the orphan drug exemption will cost $8.8 billion over a decade.[15]

III. SB26-140

The relevant portion of the bill under consideration would exempt from state affordability board review "a prescription drug that is designated as a drug for a rare disease or condition by the FDA pursuant to 21 U.S.C. sec. 360bb." There is some ambiguity in the language used here, but it appears that the drafters of the bill intend this exclusion to apply to any drug that has received an orphan drug designation regardless of 1) whether it has received approval for that indication, 2) whether it has non-orphan approvals, and 3) its costs to patients and the overall healthcare system.

As a result, SB26-140 is far broader than either the initially enacted or newly expanded exemptions for the Medicare Negotiation Program. If enacted earlier, SB26-140 would even seemingly have prevented Colorado from conducting an affordability review of Enbrel, which has an orphan indication in addition to its non-orphan indications, and which reported $4.8 billion in U.S. sales alone in 2018.[16] Passing SB26-140 into law would therefore be expected to exclude from affordability review many of the highest-cost drugs that today create affordability challenges for both patients and the overall healthcare system.

Disclosure: From April 2023 to April 2024, this author served as a Senior Advisor at the United States Department of Health and Human Services Office of the General Counsel, Centers for Medicare and Medicaid Services Division. As noted above, these comments represent my personal views, informed by my time as an academic.

---

[1] Given the complexity of these issues, my testimony here is necessarily abbreviated. I provide additional sources in the endnotes which can be consulted for greater detail.

[2] Rachel E. Sachs, *The Accidental Innovation Policymakers*, 72 Duke L.J. 1431, 1462 (2023); 21 U.S.C. § 360bb(a)(2).

[3] U.S. Gov't Accountability Office, *Orphan Drugs: FDA Could Improve Designation Review Consistency; Rare Disease Drug Development Challenges Continue*, GAO-19-83, at 2 n.3 (Nov. 2018), https://www.gao.gov/assets/gao-19-83.pdf.

[4] U.S. Gov't Accountability Office, *Rare Disease Drugs: FDA Has Steps Underway to Strengthen Coordination of Activities Supporting Drug Development*, GAO-25-106774, at fig. 2 (Nov. 2024), https://www.gao.gov/assets/gao-25-106774.pdf.

[5] *Id.*

[6] U.S. Dep't of Health & Human Servs. Office of Inspector General, *High-Expenditure Medicare Drugs Often Qualified for Orphan Drug Act Incentives Designed to Encourage the Development of Treatments for Rare Diseases*, OEI-BL-20-00080, at 4 (Sept. 2021), https://oig.hhs.gov/documents/evaluation/3209/OEI-BL-20-00080-Complete%20Report.pdf.

[7] *Id*. at 8. This analysis focused on the 20 drugs with the highest expenditures in both Part B and Part D, or 40 total. *Id.* at 6.

[8] *Id.* at 9–10.
[9] *Id.* at 10–11.
[10] Inflation Reduction Act of 2022, Pub. L. No. 117-169, § 11001, 136 Stat. 1818, 1840.
[11] Ctrs. for Medicare & Medicaid Servs., *Medicare Drug Price Negotiation Program: Revised Guidance, Implementation of Sections 1191 – 1198 of the Social Security Act for Initial Price Applicability Year 2026*, at 14 (June 30, 2023), https://www.cms.gov/files/document/revised-medicare-drug-price-negotiation-program-guidance-june-2023.pdf.
[12] AbbVie, *AbbVie Reports Full-Year and Fourth-Quarter 2022 Financial Results* (Feb. 9, 2023), https://investors.abbvie.com/news-releases/news-release-details/abbvie-reports-full-year-and-fourth-quarter-2022-financial.
[13] Merck, *Merck Announces Fourth-Quarter and Full-Year 2022 Financial Results* (Feb. 2, 2023), https://www.merck.com/news/merck-announces-fourth-quarter-and-full-year-2022-financial-results/.
[14] Kristi Martin, Emma M. Cousin, & Sean D. Sullivan, *Blockbusters And Loopholes: Expanding Exemptions In Medicare Drug Price Negotiations*, HEALTH AFF. FOREFRONT (Aug. 29, 2025), https://www.healthaffairs.org/content/forefront/blockbusters-and-loopholes-expanding-exemptions-medicare-drug-price-negotiations.
[15] Cong. Budget Office, *Revised Estimate of Changes Under the 2025 Reconciliation Act for Exemptions From Medicare Price Negotiations for Orphan Drugs* (Oct. 20, 2025), https://www.cbo.gov/publication/61818/.
[16] U.S. Dep't of Health & Human Servs. Office of Inspector General, *supra* note 6, at 10.

Chair and Members of the Committee,

My name is Greg Glischinski, and I want to thank you for reviewing this testimony and for your time considering SB26-140, which would exempt certain drugs from affordability review by the Prescription Drug Affordability Board (PDAB). I am writing to express my **opposition** to SB26-140.

Pharmaceutical companies and trade groups often present an incomplete picture when discussing the federal definition of "orphan drugs" under **FDA Title 21 U.S.C. § 360bb**. They frequently imply that orphan drugs are, by definition, prescribed to fewer than 200,000 patients in the United States. However, that is only half of the statutory framework. That determination is made at the time of the request, not based on the drug's real-world profits.

The law explicitly includes a second pathway—**the (B) clause**—which allows a drug to receive orphan designation even when it is used by **more than 200,000 patients**, so long as the manufacturer asserts that it does not reasonably expect to recover development and marketing costs from U.S. sales. The statute reads, in relevant part:

FDA Title 21 U.S.C. § 360bb: *A "rare disease or condition" means any disease or condition which (A) affects less than 200,000 persons in the United States,* ***or*** *(B) affects more than 200,000 persons in the United States* ***and*** *for which there is no reasonable expectation that the cost of developing and making the drug available in the United States will be recovered from U.S. sales.*

This distinction is critical. Orphan designation is not solely about the number of patients; it is also about a manufacturer's claimed financial expectations at the time of designation. That determination is made based on the facts and circumstances **at the time the request is submitted**, not on the drug's actual commercial performance years later.

This has created a **significant loophole**. Manufacturers can obtain orphan designation under clause (B), and then later earn billions in annual revenue once the drug is on the market. **Skyrizi** is a clear example. Public data show that approximately **86.6% of Skyrizi's global sales come from U.S. patients**, yet key information about manufacturing capacity and cost recovery is **redacted from public filings**. There is no transparent breakdown of whether most of the global supply is produced domestically or abroad (such as their Italy location), only that multiple sites are involved in manufacturing and packaging.

Despite this lack of transparency, Skyrizi is heavily marketed—many Americans see its advertisements multiple times a day—and its U.S. patient population far exceeds 200,000. This demonstrates that the orphan designation pathway is being **used in ways Congress did not intend**: to shield **highly profitable, widely used drugs** from scrutiny.

For these reasons, exempting such drugs from PDAB affordability review would further weaken oversight and allow manufacturers to continue leveraging the orphan drug framework to avoid accountability, even when their products generate enormous revenue.

I respectfully urge you to vote no SB26-140.

Sincerely,

Gregory Glischinski
5160 S. Pitkin St.
Centennial, CO 80015

To whom it may concern,

I am writing to you as as a rare disease patient, daughter and advocate to urge your support for SB26-140, which would exempt rare disease and plasma-derived treatments from the Prescription Drug Affordability Review Board (PDAB).

Patients and advocates like myself are deeply concerned that PDAB policies could unintentionally create barriers to accessing critical treatments and discourage the research and investment needed to develop life-saving therapies. For those of us living with rare diseases, access to medication is not optional, it is essential for survival.

Rare disease and plasma-derived treatments should be exempt from PDAB consideration for upper payment limits. These therapies are often complex, costly to develop, and serve small patient populations with few or no alternatives. Any changes in access could have devastating consequences.

Other states with PDAB programs, such as Oregon and Washington, have already recognized these risks and implemented exemptions for rare disease treatments. SB26-140 aligns with these approaches and helps ensure patients in our state are not left behind.

I live with Wilson's disease, a rare and fatal condition if left untreated. My medication is a critical part of my care. Without it, my disease would be life-threatening. Like many rare disease patients, I depend on consistent access to this treatment to stay healthy and alive.

This bill provides hope for patients and families like mine. It safeguards access to essential therapies while supporting the continued innovation needed to develop new treatments.

I ask that you support SB26-140 to protect patients with rare diseases and ensure we can continue to access the medications we depend on.

Thank you for your time, your service, and your consideration of this critical issue.

Sincerely,
Kelsey Pusillo
Patient ambassador Coordinator
Wilson Disease Association
1287 Loch Ness Ave
Broomfield CO 80020