



## Alliance for Patient Access

The Honorable James Coleman  
State, Veterans & Military Affairs Committee  
Chair  
200 E Colfax  
RM 346  
Denver, CO 80203

The Honorable Tom Sullivan  
State, Veterans & Military Affairs Committee  
Vice Chair  
200 E Colfax  
RM 346  
Denver, CO 80203

### **Re: SB24-060 Prescription Drug Affordability Board Exempt Orphan Drugs**

Dear Senator Coleman and Senator Sullivan:

On behalf of the Alliance for Patient Access (AfPA), I am writing to express support regarding SB24-060, which would exempt certain drugs from the Colorado Prescription Drug Affordability Review Board. While health care costs, including prescription drug costs, remain a concern, AfPA urges you to consider patients living with rare diseases and the impact a review by the PDAB could have on patient access.

#### **About AfPA**

Founded in 2006, AfPA is a national network of policy-minded health care providers who advocate for patient-centered care. AfPA supports health policies that reinforce clinical decision making, promote personalized care and protect the clinician-patient relationship. Motivated by these principles, AfPA members participate in clinician working groups, advocacy initiatives, stakeholder coalitions and the creation of educational materials.

#### **Rare Disease Considerations**

In recent years, we have seen a significant increase in innovative treatment options for rare disease patients and providers. Of the approximately 7,000 known rare diseases, fewer than 10% have an FDA-approved treatment option.<sup>1</sup> Patients with rare diseases rely on continued innovation with the goal of eventually having access to treatment options that may treat or cure their disease. However, there are concerns within the rare disease community that Prescription Drug Affordability Boards may threaten the incentive for continued innovation into rare disease treatments.

Notably, when Congress enacted the Inflation Reduction Act giving Medicare the authority to negotiate drug prices, they provided an explicit exclusion from negotiations for therapies that treat one rare disease. Congress is now considering legislation, the ORPHAN Cures Act, to expand the rare treatment exemption from Medicare drug price negotiations as outlined in the Inflation Reduction Act, by expanding rare exemption status to treatments that have more than one rare indication, as well as limiting the start of the negotiation clock until approved for a non-rare indication.

Likewise, SB24-060 is a critical step in ensuring patients living with rare diseases retain access to their current treatments, as well as the opportunity to access future treatments that have yet to be discovered.

#### **Conclusion**

We recognize the complexity of issues that come with this legislation and thank you for the opportunity to comment. The aforementioned legislation will ensure Colorado patients with rare diseases retain access to

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<sup>1</sup> <https://www.fda.gov/drugs/regulatory-science-research-and-education/rare-disease-cures-accelerator#:~:text=However%2C%20of%20the%20approximately%207%2C000,an%20FDA%2Dapproved%20treatment%20available.>

affordable treatments. If you have any questions or would like further information, please contact Casey McPherson at (202) 951-7097.

Sincerely,

A handwritten signature in cursive script that reads "Josie Cooper". The signature is written in a dark ink and is positioned below the word "Sincerely,".

Josie Cooper  
Executive Director  
Alliance for Patient Access

**CC: Senator Mark Baisley**  
**Senator Chris Hansen**  
**Senator Larry Liston**

**2/17/2024**

To Chair Coleman and Members of the Senate State, Veterans, & Military Affairs Committee:

My name is Rob Davidson. I'm the executive director of the Committee to Protect Health Care, a national organization of physicians advocating for pro-patient policies in state legislatures.

I'm also an emergency physician and just recently, I completed a shift in Colorado, where I had the opportunity – as physicians always do – to see firsthand how expensive prescription drugs can be a barrier that prevents hardworking Coloradans from getting treatment and care.

I'm here on behalf of our organization to oppose Senate Bill 60.

Senate Bill 60, simply put, will continue the crisis of unaffordable prescription drugs, while giving powerful drug companies and drug CEOs a free pass to keep putting their profits ahead of the health and safety of my patients.

Senate Bill 60 is a giveaway to Big Pharma that will prevent Colorado's Prescription Drug Affordability Board from reviewing the prices of hundreds of commonly prescribed medications – and this will prevent countless Coloradans from getting any relief from unaffordable medications.

I urge you to keep in mind that 1-in-3 Coloradans struggle to pay for their prescription medications or skip their medication altogether.

When a person skips a dose or doesn't take a dose as prescribed of a medicine designed to manage their diabetes, that patient is at risk of diabetic ketoacidosis, which can damage and destroy vital organs and lead to death.

When a person skips a dose of beta blockers for a heart disease as their doctor prescribes, that patient faces a higher risk of getting a sudden heart attack.

Yet life saving medications keep getting more expensive every year and [continue to go through the roof](#), as you no doubt hear from your own constituents.

At the same time, drug manufacturers of the first 10 drugs selected for Medicare price negotiation spent tens of billions of dollars on [activities that enriched themselves](#), including stock buybacks, lavish CEO pay and perks, and shareholder dividends.

Drug companies spent billions of dollars more to protect their profits than they did on research and development, and certainly not on reducing high drug prices.

Colorado's PDAB is beginning the important work of reining in high drug costs, providing transparency to drug pricing practices and holding drug industry CEOs accountable.

Senate Bill 60 will undo this work and harm patients because it will prevent Colorado's PDAB from requiring drug companies to charge a fair price for the most expensive medications Coloradans rely on every day.

Colorado's Prescription Drug Affordability Board is this state's only tool to hold Big Pharma accountable and rein in out-of-control drug costs.

In Colorado as in other states where legislators are working to hold drug companies accountable, Big Pharma is using every trick in the book to protect its massive profits –and we urge policymakers and citizens to be vigilant against these efforts.

Drug companies are trotting out [well-funded front groups](#) claiming to look out for patients' best interests.

Big Pharma is [peddling the falsehood](#) that high prices are necessary for innovation and reliable supply – even though we should remember that a drug like [Humira](#) costs 423% more in the United States than in Britain.

Now new research is revealing that Big Pharma is also colluding with [extremist groups and individuals](#).

Nearly 3 in 4 Coloradans from all political backgrounds want the PDAB to do its job of reining in outrageously expensive medications and hold drug companies accountable.

Senate Bill endangers Coloradans' access to affordable prescription drugs –and for this reason, the Committee urges you to vote NO and oppose this dangerous legislation.

Signed,

Rob Davidson, MD MPH

Leland M. Johnston, M.D.  
1650 38th Street; Suite 203W  
Boulder, Colorado 80301  
720-334-5251

February 16, 2024

To: Chair Coleman and Members of the Senate State, Veterans, & Military Affairs Committee

From: Leland M. Johnston, M.D. - Adult, Adolescent, Child Psychiatrist and Psychoanalyst

Big Pharma is notorious for deploying its army of lobbyists, front groups and millions and millions of dollars against pro-patient legislation such as the Prescription Drug Affordability Board – one with real teeth that can rein in costs and hold drug companies accountable.

Big Pharma's shady tactics require all of us to be vigilant – and for our elected leaders to see Senate Bill 60 for what it truly is, a backdoor, loophole-riddled giveaway that will protect drug industry profits while keeping costs sky high for patients.

Let me illustrate one red herring that drug company lobbyists and their front groups are fond of using as part of their PR campaign, the false argument of so-called orphan drugs.

Patients with rare diseases deserve access to affordable prescription drugs, as do patients with manageable chronic conditions like diabetes, heart diseases, Crohn's disease and many other conditions.

Patients with rare diseases are among the most harmed by out-of-control drug costs and they deserve access to affordable, life-saving drugs through Colorado's Prescription Drug Affordability Board.

SB 60 will render Colorado's PDAB toothless, exclude patients with rare diseases from ever benefiting from access to lower cost drugs, and prevent the PDAB from reviewing the most expensive medications.

Senate Bill 60 is part of a national strategy pushed by pharmaceutical companies – disguised as a “rare disease” bill – to make it impossible for PDABs in Colorado and across the country to bring down the cost of prescription medications.

The reality is that the current federal orphan drug system is set up to benefit Big Pharma by ensuring the most critical medications that treat serious and rare conditions are extremely profitable.

Under federal law, drug companies face no competition in the so-called rare diseases prescription drug market, allowing them to legally keep their prices high for decades.

Senate Bill 60 will prevent Colorado's Prescription Drug Affordability Board from requiring pharmaceutical companies to charge a fair price for these medications.

Senate Bill 60 will effectively slam the door in the faces of patients with rare diseases who need access to very costly medications.

Because of the devastating risks to all patients, we urge you to reject Senate Bill 60.

Sincerely,

A handwritten signature in black ink that reads "Leland M. Johnston MD". The signature is written in a cursive, flowing style.

Leland M. Johnston, M.D.

2/17/2024

To Chair Coleman and Members of the Senate State, Veterans, & Military Affairs Committee:

I am Dr. Anna Olson, MD, FACEP, FAAEM. I am Emergency Medicine Residency Trained and Board Certified, and I have spent my career fighting for the lives of people who are in their most vulnerable moments with illness and injury. I also have Relapsing/Remitting Multiple Sclerosis, for which I have taken either Rituxan or Ocrevus twice yearly since the year I was diagnosed.

For these 600mg infusions, the manufacturers typically charge \$100,000 per dose (though the opening salvo is sometimes as high as \$220,000), at which point a dirty but profitable shell game begins. This is primarily to the benefit of big pharma, but sometimes spares privately insured patients like myself from the astronomically inflated costs of life-saving drugs.

The first thing that happens is my private insurer counters with an offer of \$30,000. Having “negotiated” the rate, they then pay only \$20,000, leaving the remaining \$10,000 as the patient’s responsibility. The manufacturer takes that \$20,000 and uses \$10,000 to pay the patient’s deductible, keeping only \$10,000 for themselves. In the end, the manufacturer keeps only 10% of what they initially billed, which is clearly enough to keep their lights on, or they wouldn’t offer this arrangement.

What are my underinsured and uninsured patients asked to pay? Full price: \$200,000-\$440,000 for a single year. The average MS patient will need treatment for at least 30 years, so lifetime cost of medication could easily reach a staggering \$10M. For most Americans, that is simply out of reach, so they are left to choose between inferior medications that don’t control the disease, or they go without any treatment at all. Either way, they are left without protection from progression of disease, worsening symptoms, disability, and death. That’s just shameful, and I am counting on lawmakers like yourselves to put a stop to it.

I urge this panel to vote against Senate Bill 60.

Since the creation of Colorado’s Prescription Drug Affordability Board, the pharmaceutical industry has attempted to create loopholes to avoid accountability.

Without the light of transparency that Colorado’s PDAB can shine on Big Pharma’s pricing practices, drug companies can continue charging Coloradans excessive prices for medication.

The language in Senate Bill 60 is so broad that it will prevent the Prescription Drug Affordability Board from reviewing hundreds of commonly prescribed medications that Coloradans struggle to afford every day.

And when people can’t afford their medications, my experience as a physician is that they don’t get them or they skip doses or they split pills.

All of this amounts to non-adherence of medications as prescribed, and when people don't take their medications, they can get sicker, their health can deteriorate and people can die.

Drugs only work if people can take them, and the drug industry has created an affordability crisis that is preventing my patients and nearly one-third of all Coloradans from taking life-saving, health-improving medications.

Over the past decade, prescription drug list prices have risen by 159%, and net prices have increased by three times the rate of inflation.

On average, Coloradans pay between 65% and 85% more for the same medications than people in other countries.

According to estimates, a PDAB could save Coloradans as much as 75% on the costs of most drugs that are currently unaffordable by bringing them more in line with the costs in other countries.

An independent PDAB with the authority to research, review and receive testimony from all stakeholders in the health care ecosystem – including patients and their families – and then set upper limit payments, or caps, on the costs of the most egregiously unaffordable medications is an essential step toward breaking barriers to care.

For these reasons, I join physicians across Colorado in urging you to oppose Senate Bill 60.

Signed,

Dr. Anna Olson, MD, FACEP, FAAEM

Emergency Medicine Residency Trained and Board Certified: Fighting for your life.

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2/17/2024

Chairman Coleman and Members of the Senate State, Veterans, & Military Affairs Committee,

As a physician, I can provide firsthand accounts of how my patients' lives change when they can afford their prescribed medications. For some, access to these medications is lifesaving. That's why I was relieved when our state's leaders took action in 2021 to help patients afford their prescribed medicine by creating a Prescription Drug Affordability Board.

Now I'm concerned that the pharmaceutical industry is attempting to undercut our Board as they've tried to do in other states as well. That's why I'm submitting testimony in strong opposition to Senate Bill 60. Senate Bill 60 would harm patients like mine by giving pharmaceutical companies a nearly free pass to continue using their price-gouging tactics against them.

Throughout my years of practicing medicine, I have treated an overwhelming number of patients who struggled to, or simply could not, afford their prescribed medications. And my experience is not isolated, as one-in-three Coloradans struggles to afford their medications.

In addition to working clinically as an emergency physician at the VA, I currently am the Medical Director for the Hummingbird Initiative (HBI). The HBI, funded by the Colorado Behavioral Health Administration, is a career track program for high school students interested in Behavioral Health careers. Our program is currently in 5 high schools throughout Colorado and primarily serves historically underrepresented youth in urban and rural communities. I have seen our youth and their families struggle to maintain their health due to drug costs. Recently, a student at one of our locations fainted in class due to inability to afford his prescription medications for diabetes. Within our most vulnerable communities, the program with affording easily accessible life-sustaining medications is an epidemic and I write you today to advocate for all of them.

Prescription drugs only work when my patients can afford to take them, and when they can't, they can see their often treatable conditions worsen. Patients' health deserves to be prioritized over the pharmaceutical industry's profits.

Unfortunately, Senate Bill 60 would be a win for the pharmaceutical industry's bottom line — not for patients. If the state's Prescription Drug Affordability Board can't set fair rates on high-cost medicines that my patients rely on every day, then the only tool our state has to hold Big Pharma accountable is essentially gutted. The loophole Senate Bill 60 would create would allow pharmaceutical companies to continue charging patients like mine excessive amounts for their medication. It's up to our state's leaders to rein in out-of-control drug prices and ensure that Big Pharma is held accountable, and that means voting no on Senate Bill 60.

Thank you for your time and consideration of my testimony.

Signed,

Dr. Katie Bakes

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2/17/2024

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Thank you for your time and consideration of my testimony.

Signed,

Dr. Katie Bakes

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**02/22/2024**

To Chair Coleman and Members of the Senate State, Veterans, & Military Affairs Committee,

My name is Dr. Kyle Leggott, I am a Family Medicine physician caring for patients in the clinic and in the hospital. I am submitting written testimony on behalf of myself in opposition to SB24-060 because I believe it will severely weaken the ability of the Prescription Drug Affordability Board (PDAB) to address the high cost of prescription medications for my patients.

In 2021, Governor Polis and legislative leaders like yourselves created the PDAB to rein in out-of-control prescription medication costs. Like an overwhelming majority of Coloradans, physicians like myself supported the creation of this Board. And physicians across the state do not want the Board's work to be hindered by legislation that carves out some of the highest cost prescription drugs and hinders the Board's ability to rein in costs.

SB24-060 would essentially strip Colorado's PDAB of its ability to review prices of hundreds of commonly prescribed drugs and set more affordable upper payment limits for them.

I've seen firsthand the negative impact high prices for prescription medication has on patients, and understand how vital this Board is to ensuring they can afford them. I have cared for patients who take Humira for their Rheumatoid Arthritis, an autoimmune condition in which the body's immune system attacks joints, and for many it has worked wonders to help control their joint pain, swelling, and stiffness. But for some, the cost of Humira can suddenly change, whether it be a price change from the drug manufacturer or a change in insurance coverage. The sudden inability to afford Humira and medications like it can lead to dramatic worsening of pain and quality of life.

Humira was originally approved by the FDA to treat millions of Americans with Rheumatoid Arthritis but in 2005 the drug's manufacturer asked the FDA to designate Humira as an "orphan drug" to treat Juvenile Rheumatoid Arthritis, a condition which affects far fewer patients nationwide. This bill would make a carve out in the Board for "orphan drugs", medications intended to treat rare diseases, but in actuality are used to treat many common conditions. Studies have shown that 75% of the sales for "orphan drugs" are for treating common medical conditions.

The cost of prescription drug list prices have risen 159% over the last decade, leading more than half of Colorado patients to worry about how they will afford their medications. And their access to affordable, life saving drugs will continue to be limited if SB24-060 moves forward. These patients would be excluded from ever benefitting from access to lower cost drugs.

I ask that you vote against this bill to protect Colorado patients. Thank you for your time and consideration of my testimony.

Signed,

Kyle Leggott, MD



**Submitted for Written Testimony:  
Colorado Senate State, Veterans, & Military Affairs Committee  
Meeting, February 22, 2024**

**Mailing Address:**

Attn: Jen Laws  
PO Box 3009  
Slidell, LA 70459

**Chief Executive Officer:**

Jen Laws  
Phone: (313) 333-8534  
Fax: (646) 786-3825  
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**National Programs:**

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PDAB Action Center  
Transgender Leadership in HIV Advocacy  
HIV/HCV Co-Infection Watch

**National Groups:**

Hepatitis Education, Advocacy & Leadership  
(HEAL) Group  
Industry Advisory Group (IAG)  
National ADAP Working Group (NAWG)

January 21, 2024

Colorado Senate  
Senate State, Veterans, & Military Affairs Committee  
State Capitol Building  
200E. Colfax Avenue  
Denver, Colorado 80203

**RE: SB24-60 – Patient Support for Orphan Drug Exemptions**

Dear Honorable Chair Coleman, Senators serving the State, Veterans, & Military Affairs Committee, and respected staff,

**About Community Access National Network:** CANN is a 27-year-old national nonprofit organization focusing on public policy issues relating to HIV/AIDS and viral hepatitis from the patient perspective. CANN's mission is to define, promote, and improve access to healthcare services and supports for people living with HIV/AIDS and/or viral hepatitis through advocacy, education, and networking.

**CANN SUPPORTS** the effort to protect orphan drugs and rare disease patients from unknown and potentially harmful impacts to accessing life-saving and live-improving care.

Accessing HIV-related care is not dissimilar to the needs rare disease patients and their families face. Challenges throughout the drug supply and healthcare delivery system abound, from all treatment options being deemed “specialty” to desperately awaiting the next innovation to ease disease burdens on our bodies, our ability to be involved in society, and the personal costs to our families. We are also well-familiar with the ins and outs of navigating care and intimately familiar with the variety of interests involved throughout the supply chain. We are also familiar with well-intended efforts to ease these burdens and when those efforts can go...sideways.

This is precisely why the Board’s Advisory Committee recommended to the Board to *not* select rare disease/orphan drugs for the first round of “affordability reviews”. Instead of heeding the recommendations, the Board selected not just one but multiple medications with an orphan drug status. For these and the following reasons we urge this committee to advance SB24-60 **FAVORABLY**.

Because of the unproven nature of PDABs and the establishment of an “upper payment limit” in limiting the potential of unintended consequences exposure to patients experiencing rare and chronic conditions, health conditions of public

health concern as with HIV, and extraordinary nature of each of these, we sincerely request the legislature find itself aligned with the recommendations of the Advisory Committee: support the efforts of SB 24-60 and cement in statute the advice provided by the experts appointed under statutory authority.

The establishment of a Prescription Drug Affordability Board, without sufficient guardrails, continues to risk access to care for the most marginalized patients and those with exceptional health conditions across Colorado. The Board does not have any mechanism for assessment of impact of establishing an “upper payment limit”. An idea is well and good but implementation matters and no such provision exists mandating the Board monitor for any unintended consequences as a result of establishing a “UPL”. If the Legislature, Governor, or Board members wish to tout the work of the Board as anything other than a talking point, the Board should be directed to establish such monitoring metrics and means for rescinding *prior* to instituting any “UPL”. CANN believes in the good faith behind these efforts. However, no similar good faith can be extended when there is no mechanism to ensure the intentions of the Legislature and even individual Board members are actually achieved exists.

Because of the unproven nature of PDABs and the establishment of an “upper payment limit” in limiting the exposure of patients experiencing rare and chronic conditions, health conditions of public health concern as with HIV, and extraordinary nature of each of these, we sincerely request the legislature find itself aligned with the recommendations of the Advisory Committee: support the efforts of SB 24-60 and cement in statute the advice provided by the experts appointed under statutory authority.

As always, CANN is happy to answer questions with regard to our concerns and continue in on-going conversation with legislators as to tangible solutions affecting patient access to care.

Ever yours in service,

A handwritten signature in black ink, appearing to read "Jen Laws", written in a cursive style.

Jen Laws  
President & CEO



Colorado Senate State, Veterans, & Military Affairs Committee  
200 E Colfax Avenue  
Denver, CO 80203

**RE: Support for SB24-060**

Feb. 8, 2024

Chair Coleman, Vice Chair Sullivan, and members of the committee,

On behalf of the Chronic Disease Coalition, thank you for the opportunity to provide support for SB24-060 which would protect existing and future rare disease treatments from the unintended consequences of regulation by Colorado's Prescription Drug Affordability Review Board.

The Chronic Disease Coalition is a national nonprofit organization dedicated to raising the patient voice and perspective in healthcare policymaking. The coalition was founded in 2015 to advocate for people living with long-term or lifelong health conditions. Our patient advisors and partners represent common diseases (e.g., diabetes, kidney disease, arthritis), rare diseases (e.g., Guillain-Barré syndrome, hypoparathyroidism), and many other conditions whose scale and scope are still not understood.

We have an obligation to the next generation of patients to encourage the development of the next generation of treatments. We must recognize that all our innovations — for diseases known and unknown — come from the private sector. There is a pressing need to balance the need for affordable medication with the need to develop better treatments, especially for those living with rare diseases, for which effective treatment can be elusive.

Developing treatments for rare diseases can be exceptionally costly due to the limited patient population available for clinical trials and the complexity of the treatment itself. Pharmaceutical companies invest significant resources into research and development for these treatments, and price controls hinder their ability to recoup these investments — which disadvantages current and future rare disease patients.

This bill is an important protection for rare disease patients in Colorado who don't have alternative treatment options. Often, when price controls are implemented on treatments for chronic disease, it could affect the cost of other drugs in similar categories. The stakes are higher for those living with rare disease, who typically do not have as many treatment options as other chronic patients.

Colorado is looked to by other states as a model for PDAB policy and governance, but we need to do this work in the real context of the healthcare system and by focusing on reforms that immediately and directly benefit patients. By exempting rare disease drugs from the possibility of price controls, we protect this lifesaving access. We appreciate your public service as we all work toward the shared goal of more effective, more affordable health care for Coloradans.

Sincerely,

Nathaniel Brown  
Director of Advocacy  
[nathaniel@chronicdiseasecoalition.org](mailto:nathaniel@chronicdiseasecoalition.org)  
(971) 219.5561



Colorado Senate State, Veterans, & Military Affairs Committee  
200 E Colfax Avenue  
Denver, CO 80203

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Sincerely,

Nathaniel Brown  
Director of Advocacy  
[nathaniel@chronicdiseasecoalition.org](mailto:nathaniel@chronicdiseasecoalition.org)  
(971) 219.5561

February 21, 2024

**Subject: Concerns about Colorado Prescription Drug Affordability Board (PDAB)**

Chair Coleman, Vice Chair Sullivan, and Distinguished Members of the Colorado State, Veteran, and Military Affairs Committee,

The Alliance for Health Innovation (Alliance) is a group of diverse cross-sector stakeholders representing patients, providers, caregivers, academia, biopharmaceutical innovators, and business communities.

Led by the Global Coalition on Aging (GCOA), the Alliance is committed to establishing the importance of innovation in achieving healthy aging and advocates for state policy solutions that support a thriving innovation sector that enables Coloradans and other communities to live longer – and healthier – lives.

Colorado is currently ranked as the best state in the nation in which to age; we are concerned that the possibility of Colorado's Prescription Drug Affordability Board (PDAB) establishing Upper Payment Limits (UPLs) on any prescription drugs would limit access to prescription drugs that patients vitally need and harm Colorado's reputation as one of the best places in the US to age healthily.

As you prepare to hear public comments on the proposal to exempt orphan drugs from the affordability review process (SB24-060), we write to share our concerns and suggest that the Committee consider amending the current proposal to include exemptions for the six protected classes of drugs established by the Centers for Medicare & Medicaid Services (CMS).

Excluding antidepressants, antipsychotics, anticonvulsants, immunosuppressants for treatment of transplant rejection, antiretrovirals, and antineoplastics from the affordability review process would be in line with the position of the US Congress, which has recognized that limiting access to these drugs would be devastating to patients and the broader healthcare system. Furthermore, limiting access to these drugs would exacerbate health inequities for those who rely on such medications.

While we applaud the proposal to create an exemption for orphan drugs, this does not alleviate our broader concern that setting a UPL for any drug will disproportionately affect the disadvantaged populations these policies are meant to protect.



We believe that a UPL would likely decrease reimbursements from payers to pharmacies and providers for certain drugs, leading to manufacturers leaving the market in Colorado. Like the importation of prescription drugs, cooperation from all stakeholders in the healthcare system is required when states attempt to make changes to a federally regulated system.

While setting a UPL may save payers in the short term, the Alliance believes pharmacies and providers will be forced to respond by limiting patient access to newer and often more effective medicines if not adequately reimbursed, leading to significant patient access restrictions. From that perspective, a UPL harms patients by restricting access to drugs that greatly improve their quality of life and creates higher healthcare spending throughout the healthcare system due to increased healthcare needs.

Many diseases that once burdened aging populations have evolved into manageable chronic conditions due to the development of safer, more effective treatments. At the same time, there remains a vast unmet patient need for new solutions to complex, age-related health challenges, including Alzheimer's disease, HIV, heart disease, cancer, bone health, and more. Unfortunately, price limits will undercut the incentives to research and develop such innovations and derail progress toward achieving healthier, more productive societies.

Vulnerable populations – such as older adults living with HIV – are even more dependent on access to innovative medicines than others who suffer from chronic conditions. Thanks to years of biomedical investment and innovation, a person with HIV who starts treatment soon after their diagnosis can expect to live the same lifespan as an HIV-negative person.

However, as people with HIV live longer, they can develop comorbidities that affect their health-related quality of life and are costly to treat. People living with HIV are more likely to develop additional health issues as they age and tend to develop them earlier than people who do not have HIV.

As a result of the work of the PDAB, life-saving innovations could become inaccessible to Coloradans who depend on them to manage chronic and, in some cases, life-threatening conditions.

Thank you for allowing us to share our concerns and for your commitment to finding solutions to Colorado patients' affordability and access challenges. We would be happy to discuss these concerns further or answer any questions.

Sincerely,

Michiel Peters, Head of Advocacy Initiatives, Global Coalition on Aging

To Chair Coleman and Members of the Senate State, Veterans, & Military Affairs Committee:

My name is Lauren Bull. I am a physician practicing locally here in Denver. I completed my medical school training at the University of Oklahoma and my residency training in Family Medicine at the University of Colorado in 2019.

When I chose medicine as a career, I did so because I wanted to care for the health and wellbeing of patients, to find solutions to their health problems, to focus on prevention, and to do whatever I could to make people's lives a little better and more hopeful.

Unfortunately, the cost of medications and challenges navigating this for insured, under-insured, and uninsured patients has been a constant theme since I started my training. Myself and my staff members have been forced to play investigator, searching out ways to help our patients find medication cost savings because a medication I prescribed them was something they simply couldn't afford.

I've fielded too many calls from patients in a panic while they're at the pharmacy because they got sticker shock for an inhaler they need for their asthma. Too many of my patients tell me how they have been forced to skip doses or not fill a prescription because they just couldn't pay for their medications. Or unfortunately most commonly, I do not know there's an issue until months later when a patient tells me they never were able to actually start that inhaler or I can't figure out why I can't get their diabetes under better control until they disclose they've been rationing their insulin.

So my team and I search for financial assistance resources or hunt for rebates to help with the costs, often without finding a good solution. And my patients suffer.

Health care should not be this way. Colorado's PDAB, with the authority to investigate drug pricing practice and their impact on patients and set caps on egregiously expensive drugs, is an important positive development in the effort to make health care more affordable and accessible to more people across Colorado.

For Coloradans with cancer, the treatment Keytruda costs \$150,000 per year. Coloradans with muscular atrophy may have to shell out \$2.25 million for a one-time treatment. Coloradans with cystic fibrosis could spend more than \$300,000 per year.

We heard earlier that Humira costs 400% more in the U.S. than in Britain – and Humira has so far raked in \$200 billion for AbbVie.

Senate Bill 60 unfortunately is operating under the assumption that these drugs for rare diseases are actually used to treat rare diseases, when in reality many of these drugs will go on to show efficacy for treating many common conditions and be used by large numbers of patients. Humira is a great example. Humira was initially designed as a treatment for rheumatoid arthritis, however it is now approved as a treatment for many conditions including psoriatic arthritis, Crohn's disease, ulcerative colitis, plaque psoriasis, uveitis, and hidradenitis

suppurativa. Humira is not a medication for a rare disease, but rather a widely used medication for multiple common health conditions.

Pharmaceutical companies know this, but continue to exploit the exception for rare diseases or “orphan drugs” to their immense benefit. Senate Bill 60 will simply continue this unfair, egregious imbalance, where patients go bankrupt if they want to live, while CEOs of Big Pharma’s [top companies averaged around \\$16 million](#) in compensation in 2019.

The good people of Colorado and my patients deserve better. They deserve affordable medications with appropriate oversight from the Colorado PDAB.

Please reject Senate Bill 60.

Signed,

Lauren Bull, MD  
Family Medicine Physician

To Chair Coleman and Members of the Senate State, Veterans, & Military Affairs Committee:

As a physician, I applaud Colorado policymakers and legislators for their work in creating and implementing our state's Prescription Drug Affordability Board. I have seen too many patients struggle to pay for medications I prescribe for them. I have cared for too many people who have been forced to ration their care because their medications cost too much, only to experience setbacks in the management of their care.

As first passed in 2021, Colorado's PDAB represents an important step toward reducing the outrageous costs of prescription drugs and helping Colorado families afford their medications. Unfortunately, drug companies and their lobbyists are trying to undermine the important work of the PDAB. Senate Bill 60 is an example of drug industry-friendly legislation masquerading as cover for patients with rare diseases, when it will effectively hamstring the PDAB's ability to hold high costs in check.

Legislators should reject SB60 and ensure Colorado's PDAB retains all its authority to research and review data, act independently of politics and corporate special interests, and cap the costs of prescription drugs that the panel deems unaffordable. Patients with rare diseases are the ones who face the greatest barriers in accessing astronomically expensive medications – and often medications that are kept inflated under monopoly conditions. Patients across Colorado deserve access to affordable prescription drugs and SB60 stands in the way of this important goal.

Signed,  
Maria Chansky, MD  
Family Medicine

To Chair Coleman and Members of the Senate State, Veterans, & Military Affairs Committee:

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Signed,  
Maria Chansky, MD  
Family Medicine

Testimony of Jane Horvath  
to the Colorado Senate State, Veteran, and Military Committee  
February 22, 2024  
Concerning CO SB24-060, Orphan Drug Exemption from Prescription Drug Affordability Board  
Consideration

Thank you Chair Coleman and members of this Committee for the opportunity to provide information about the orphan drug business model. I am Jane Horvath of Horvath Health Policy. I consult with state policymakers and consumers on prescription drug cost containment, notably upper payment limits. I have considerable experience in prescription drug affordability, including the creation of the Medicaid drug rebate program while representing the Nation's Medicaid directors, creation of the Vaccines for Children program while staff to the US Senate Finance Committee, and implementation of the Medicare Part D program while an employee of Merck.

I write today about CO SB24-060 which would exempt all US orphan drugs from the Colorado Prescription Drug Affordability Board (PDAB) review. I suggest there are some key considerations when thinking about the impact of this legislation.

*Orphan drug development is a financial boon to the industry. It is not the fragile, risky, tenuous market the industry wants us to believe it is. Here is why:*

- Orphan drugs carry much less financial risk than non-orphans because
  - clinical trials are much less costly,
  - orphans get much faster approval,
  - orphans have much higher probability of FDA approval than non-orphan products.
- Orphan drugs are among the top revenue drugs in the world. They are global blockbusters. Here are three of many possible examples of orphan block busters:
  - **Humira** is an orphan drug and was the global #1 selling drug in 2022 with sales of ~\$20B. It treats more than ten non-orphan and orphan conditions.
  - **Keytruda** is expected to replace Humira as #1. It is an orphan drug which treats more than ten orphan and non-orphan cancers.
  - **Trikafta** is #3 in global sales of ~10B in 2023. Unlike Humira and many other orphan drugs, it has only orphan uses. It is #3 in the world solely based on price, not volume.

*Statewide upper payment limits (UPLs) are a market reset*

- UPLs protect the consumer from the anti-consumer behavior that results from the ongoing market struggle between PBMs and manufacturers.
- UPLs are the beginning point for commercial market negotiations and profits, but the consumer never pays more than the UPL.
- UPLs are not intended to harm drug companies, but rather to increase patient access to a product and manufacturer product access to the market as a result.

*Summary*

Exempting orphan drugs will significantly restrict the number of prescription drugs that can be reviewed, made affordable, and thereby disrupt many of the dysfunctional elements of the pharmaceutical market that harm Colorado consumers, and which result from high costs.

I would be pleased to provide any additional information that may help inform the Committee on the exceptional financial success of the US orphan drug market.

Jane Horvath

Principal, Horvath Health Policy  
horvathhealthpolicy@gmail.com

February 22, 2024

Members of the Senate State, Veterans and Military Affairs Committee,

Thank you for your time and consideration of our comments relating to SB24-060, Prescription Drug Affordability Board Exempt Orphan Drugs. National Jewish Health is supportive of this bill and hopes that you will join us in our support.

National Jewish Health is the leading respiratory hospital in the nation. We serve by providing the best integrated and innovative care for patients and their families; by understanding and finding cures for the diseases we research; and, by educating and training the next generation of health care professionals to be leaders in medicine and science.

During the first round of PDAB affordability reviews this summer and fall, National Jewish Health provided expert testimony and guidance to the Board regarding the unique nature of the rare disease drug, Trikafta. Several of our physicians in the cystic fibrosis clinic have been at the forefront of treating patients with this amazing, life changing drug.

It is hard to emphasize the profound impact that the PDAB review of Trikafta had on our patients and caregivers. The process revealed how very vulnerable they feel with even the possibility that such a lifesaving drug could be withdrawn because of PDAB actions.

During this process CF patients shared their traumatic memories of fighting for life with CF pre-Trikafta. They spoke of a lifetime battle with the disease and described managing CF as a full-time job. In addition, they stated that the very experience of needing to remember and retell their stories as traumatic, painful, stressful, and PTSD-inducing.

Rare disease drugs impact fewer than 200,000 people across the country. We assert that the focus of the PDAB should rightfully be on drugs that impact a larger population.

We stand with rare disease advocates in support of an exemption for orphan drugs because we understand firsthand how critical these medications are to treating rare diseases and saving lives. This bill provides hope for patients and families with rare diseases by maintaining access to the life saving and life changing treatments. This also works to ensure the continued development of groundbreaking drugs by encouraging ongoing research and development.

We respectfully ask for you to support SB24-060.

Thank you,

**Kevin K. Brown, M.D.**  
Chair, Department of Medicine

**National Jewish Health**  
1400 Jackson St.  
Denver, Colorado 80206

Thursday, February 22, 2024

Senate Committee on State, Veterans, & Military Affairs  
Colorado General Assembly  
200 E. Colfax Ave. Denver, CO 80203

**RE: Support for SB24-060 PDAB Exempt Orphan Drugs**

Dear Chair Coleman, Vice Chair Sullivan, and Members of the Committee:

Children's Hospital Colorado writes in support of Senate Bill 24-060. Thank you for accepting written testimony and many thanks to the sponsors and advocates for all their work on this important proposal to protect access to the drugs and therapies that treat rare conditions.

Children's Hospital Colorado is one of the leading, not-for-profit pediatric healthcare providers in the country, as well as the largest provider of Medicaid services for children in the state of Colorado. We care deeply about the health and well-being of children in our state and our region and desire to preserve and expand their access to care.

We share many of the concerns about drug affordability that prompted the legislature to design the Prescription Drug Affordability Board (PDAB). Many prescription drugs in the United States, especially newer and more specialized drugs, are very expensive. The challenges of drug affordability are borne by patients, families, providers, and the healthcare system at large.

At the same time that we recognize the Board's interest in addressing drug affordability, we also believe it is critical to advocate for the medical needs of the patients and families we serve, particularly those who have rare diseases treated with orphan drugs.

We shared with the Board our concerns about the risk associated with setting upper payment limits for drugs that are used to treat these rare conditions, and the high likelihood that doing so would create gaps in access to care for patients in Colorado. One drug in particular was of special concern for us – Trikafta (elexacaftor/tezacaftor/ivacaftor), a medication used to treat cystic fibrosis. This is a drug which is effective for about 90% of patients with cystic fibrosis, has resulted in significant reductions in inpatient stays, has dramatically extended life expectancy, decreased complications, and reduced by roughly 80% the likelihood of a patient with cystic fibrosis requiring a lung transplant.

We are deeply thankful to the Board for its careful consideration of that drug and for their ultimate decision to avoid advancing any policy that would cause gaps in access to care for patients in Colorado who have cystic fibrosis.

While we are thankful for the Board's ultimate decision, we also see this situation as having been a near-miss. Had medical providers – and more importantly, patients with cystic fibrosis – not mobilized so vocally against the setting of an upper payment limit, well-intentioned administrative action could have resulted in a major gap in access to care, with health- and life-threatening consequences.

Similar principles apply to other rare disease as apply to the case of Trikafta for cystic fibrosis; most rare diseases have a limited number of treatment options available, and oftentimes only a single highly effective treatment, and so it is critical to ensure stable access to the best clinical options available. We believe the most important change the bill can make is to protect patient access to treatment by excluding rare disease drugs with no other therapeutic alternatives from the scope of the PDAB. We believe this both focuses the PDAB on the areas where the greatest good can be done from an affordability perspective, while also limiting the future potential for situations that could disrupt access to critically needed medications.

Again, Children's Hospital Colorado respectfully asks the members of the Committee for a "yes" vote on Senate Bill 060 to protect access to drugs and therapies for rare conditions.

Thank you very much for accepting written testimony, and please reach out with any questions you may have.

Sincerely,

A handwritten signature in blue ink that reads "SAGEL". The signature is stylized with a large, sweeping initial "S" that extends to the left and underlines the name.

Scott D. Sagel, MD, PhD  
Professor of Pediatrics  
Director, University of Colorado Cystic Fibrosis Center  
Children's Hospital Colorado  
University of Colorado School of Medicine

**Senate State, Veterans, & Military Affairs**

**02/22/2024 01:30 PM**

**SB24-060 Rx Drug Affordability Board Exempt Orphan Drugs**

**Typed Text of Testimony Submitted**

<b>Name, Position, Representing</b>	<b>Typed Text of Testimony</b>
<p>Michiel Peters Amend Global Coalition on Aging Alliance for Health Innovation</p>	<p>The Alliance for Health Innovation (Alliance) is a group of diverse cross-sector stakeholders representing patients, providers, caregivers, academia, biopharmaceutical innovators, and business communities.</p> <p>Led by the Global Coalition on Aging (GCOA), the Alliance is committed to establishing the importance of innovation in achieving healthy aging and advocates for state policy solutions that support a thriving innovation sector that enables Coloradans and other communities to live longer – and healthier – lives.</p> <p>Colorado is currently ranked as the best state in the nation in which to age; we are concerned that the possibility of Colorado’s Prescription Drug Affordability Board (PDAB) establishing Upper Payment Limits (UPLs) on any prescription drugs would limit access to prescription drugs that patients vitally need and harm Colorado’s reputation as one of the best places in the US to age healthily.</p> <p>As you prepare to hear public comments on the proposal to exempt orphan drugs from the affordability review process (SB24-060), we write to share our concerns and suggest that the Committee consider amending the current proposal to include exemptions for the six protected classes of drugs established by the Centers for Medicare &amp; Medicaid Services (CMS).</p> <p>Thank you for allowing us to share our concerns and for your commitment to finding solutions to Colorado patients’ affordability and access challenges. We would be happy to discuss these concerns further or answer any questions.</p>
<p>Shawna Grieger For themselves</p>	<p>Honorable Members of the Senate State, Veterans, &amp; Military Affairs</p> <p>As a mother of a child battling a rare disease, I stand before you today to share my firsthand experience with the Prescription Drug Affordability Board (PDAB) and express my concerns regarding the</p>

	<p>potential implications of adding an upper payment limit on access to life-saving medications for individuals like my daughter.</p> <p>Navigating the complexities of PDAB's review process is not unfamiliar to me and countless other patients. We understand the critical importance of ensuring access to essential medications without undue financial burdens. Recently, a group of patients, including myself, advocated for Trikafta, a vital drug for treating Cystic Fibrosis, to be excluded from PDAB's review. Fortunately, PDAB recognized Trikafta's affordability and refrained from imposing an upper payment limit.</p> <p>However, my apprehension stems from the fact that patients with rare diseases often struggle to advocate effectively due to the rarity and complexity of their conditions. As a result, their voices may go unheard, leaving them vulnerable to potentially detrimental decisions by PDAB.</p> <p>I offer this testimony as a plea on behalf of those who may not have the opportunity to speak out against PDAB's policies. It is imperative that we safeguard access to life-saving medications for all patients, especially those grappling with rare diseases. Adding an upper payment limit could pose insurmountable barriers to accessing necessary treatments, jeopardizing the lives of countless individuals.</p> <p>I emphasize that SB24-060 does not undermine PDAB's vital functions but rather ensures that our most vulnerable patients can access necessary medications without undue barriers. Therefore, I urge all committee members to support SB24-060 and ensure that patients with rare diseases have access to the life-saving drugs they desperately need.</p> <p>Thank you for your attention to this critical matter.</p> <p>Sincerely, Shawna Grieger</p>
<p>Toni Mulroy</p>	<p>Rare diseases are so complex, they are not black and white. There is so much more to understanding the costs of these drugs. There are</p>

<p>For themselves</p>	<p>many layers to rare diseases that need to be factored in rather than just the costs of a drug.</p> <p>The medications give many rare disease patients the ability to work and do everyday tasks that you and I take for granted. For example, going to the grocery store, doing laundry, or walking up a flight of stairs. My niece was on her way to having a lung transplant and being hospitalized several times in a year with Cystic Fibrosis until Trikafta literally saved her. She now can do the simple tasks and works a full time job. Without the "orphan drug"-Trikafta, she was on oxygen and not able to complete these everyday tasks.</p> <p>The trauma and stress the Cystic Fibrosis community went through while PDAB was deciding whether or not to review Trikafta was awful. This community has to relive details of their struggles and we're fearful that the life saving drug could be taken away from them. I would not want to see any other rare disease community have to experience that and the stress of these drugs being taken away from them..</p> <p>Please pass this bill to exclude rare diseases and orphan drugs.</p> <p>Thank you, Toni Mulroy 970-214-7773 Weld County</p>
<p>Joseph Trippet For themselves</p>	<p>As a caregiver of someone living with a rare disease, I'm writing to urge your support of SB24-060, a bill that would protect patient access to life-saving treatments for rare disease patients.</p> <p>An estimated 1 in 10 people is living with a rare disease, but more than 90% of rare diseases don't have an approved treatment.</p> <p>That's because developing rare disease treatments is uniquely challenging and complicated by poor disease understanding, provider knowledge, and difficulties in clinical trial recruitment.</p> <p>Colorado's PDAB adds yet another hurdle, leaving patients and their families waiting for the next breakthrough treatment.</p>

	<p>The CF drug Trikafta has saved my daughter's life and she was taken off the lung transplant list. It has been a miracle drug. Please be aware that setting an Upper Payment limit will make this drug unavailable to her and many other CF patients in the state. Two other states – Oregon and Washington – have recognized the unique challenges of developing rare disease treatments and have excluded rare disease drugs from their PDABs.</p> <p>Please stand with rare disease patients and their families and vote yes on SB24-060.</p>
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February 8, 2024

The Honorable Senator James Coleman  
Chair, Colorado Senate Committee on State, Veterans, and Military Affairs  
Old Supreme Court, Colorado State Capitol  
200 East Colfax Ave.  
Denver, CO 80203

**RE: SUPPORT FOR SB24-060, PRESCRIPTION DRUG AFFORDABILITY BOARD EXEMPT ORPHAN DRUGS**

Dear Chairman Coleman and Members of the Committee;

I write in support of SB24-060 and similarly request your support for this critical and time sensitive piece of legislation. This bill would provide a fix to an unintended consequence that arose with the creation of a Colorado Prescription Drug Affordability Board. We applaud legislative efforts to meaningfully address health care costs, however, we always advocate for strong consideration around patient impact. The PDAB as established in Colorado lacks the protections necessary for Coloradans living with rare diseases, like ALS, where treatment options are few and far between. Last year, the initial PDAB list of drugs up for review in Colorado disproportionately included rare therapies, most used by fewer than 100 Coloradans. The stress caused by this activity reverberated across the rare disease community and patients, loved ones, and care providers will remain on edge until a fix is cemented.

ALS, or amyotrophic lateral sclerosis, is a rare, progressive neurodegenerative disease that affects nerve cells in the brain and spinal cord. It is a devastating condition that leads to the gradual loss of muscle function, eventually rendering individuals unable to speak, eat, or breathe independently. When a Coloradoan is diagnosed with ALS, they are told to expect to live 2-5 years. There is no cure for ALS. There are, however, treatment options that are proven to extend life and new therapies are in development that have the potential to stave off the onset of ALS altogether.

We urge you to navigate this issue with great attention to and caution for vulnerable Coloradoans so as to assuage fears of being left behind and without any treatment options when already faced with debilitating and devastating diseases. We applaud Senators Kirkmeyer, Ginal, Michaelson Jenet, Rich, and Zenzinger and Representatives Hartsook, Duran, Bradfield, and Jodeh for sponsoring this legislation and respectfully request full committee support of this bill.

Regards,

Kara Nett Hinkley, MPP  
National Vice President of State Policy  
The ALS Association  
828-808-3941  
[kara.hinkley@als.org](mailto:kara.hinkley@als.org)  
[www.als.org](http://www.als.org)



February 22, 2024

The Honorable Senator James Coleman  
Chair, Colorado Senate Committee on State, Veterans, and Military Affairs  
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February 22, 2024

Chair Coleman and Members of the Senate State, Veterans, & Military Affairs Committee,

I am writing to share why I strongly OPPOSE Senate Bill 60.

I believe this bill was brought forth in good faith to help patients, BUT, As a physician, I can attest that Senate Bill 60 would PREVENT many of my patients from being able to AFFORD their prescribed medication needed to live their best lives.

AND This Bill would GUT the Prescription Drug Affordability Board (PDAB) by creating a large loop hole for rare drugs. Rare drugs are not rare! There are over 6000 drugs which have been classified as "rare or orphan drugs" since 1983.

Despite what the pharmaceutical industry claims, patients with rare diseases are among the most harmed by these skyrocketing drug costs. If this bill passes, these patients will be excluded from the work of the Board

This would be a TERRIBLE PRECEDENT for the legislature to enumerate details on specific medications.

We have a PDAB Board of 5 voting members and 15 advisors who are Subject Matter Experts. They review medications and determine affordability. For example they completed an affordability review of Trikafta for Cystic Fibrosis and determined it IS affordable for patients because of access to patient assistance programs. We should let the board of experts do their job.

It's estimated that the Board could save your constituents as much as 75% on the costs of most unaffordable drugs. Coloradans pay between 65% and 85% more for the same medication as residents of other countries. Already, one-in-three Coloradans struggle to afford their prescriptions, we need this Board to be able to do its job  
It's up to our state's leaders to lower the costs of prescription drugs.

Our PDAB Board, which Coloradans resoundingly supported when it was created in 2021, is Colorado's ONLY defense against the pharmaceutical industry's price-gouging tactics.

Medication only works when patients can afford to take them and These medications work. Without them, my patients get worse and often end up coming to the Emergency Department or admitted to the hospital, driving up health care costs.

A NO VOTE on Senate Bill 60 will allow the state's Prescription Drug Affordability Board to function to reduce the costs of expensive prescription drugs for patients like mine across the state. Don't GUT the PDAB.

That's why I am urging each of you to vote AGAINST this legislation.

Thank you for your consideration.

Kristen Nordenholz, MD