

Senate Health and Human Services Committee
200 E Colfax Avenue
Denver, CO 80203

March 30, 2023

Honorable Members of the Senate Health and Human Services Committee,

On behalf of the 1.2 million Colorado residents with doctor-diagnosed arthritis, thank you for the opportunity to submit testimony in support of SB 195, which addresses copay accumulator adjustment programs.

These programs prevent any co-payment assistance that may be available for high-cost specialty drugs from counting towards a patient's deductible or maximum out-of-pocket expenses. Many pharmaceutical manufacturers offer co-pay cards that help cover a patient's portion of drug costs. Traditionally, pharmacy benefit managers have allowed these co-payment card payments to count toward the deductible required by a patient's health insurance plan. With an accumulator adjustment program, patients are still allowed to apply the co-payment card benefits to pay for their medications up to the full limit of the cards, but when that limit is met, the patient is required to pay their full deductible before cost-sharing protections kick in.

Currently, the state of Colorado does not have a law to ensure that health insurers count co-payment assistance towards a patient's cost-sharing requirements. Now more than ever, it will be important for the Colorado State Legislature to act given 3 out of the 6 insurers in the state have an accumulator adjustment program.¹

Legislation is necessary on this issue as patients are often unaware they are enrolled in one of these programs until they go to the pharmacy counter and realize they must pay the full cost of their medication, which can lead them to abandon or delay their prescription. These programs can be called different names, are often marketed as a positive benefit, and are disclosed many pages into plan materials, leading to a lack of awareness about them to patients.

In a recent Arthritis Foundation survey, 37% of patients reported they had trouble affording their out-of-pocket costs. Of those, 54% say they have incurred debt or suffered financial hardship because of it. The Arthritis Foundation also surveyed in 2017

¹ Institute, T. A. (February 2023). *Discriminatory Copay Policies Undermine Coverage for People with Chronic Illness*. National Policy Office. Washington, DC: The Aids Institute. Retrieved from <https://aidsinstitute.net/documents/TAI-Report-Copay-Accumulator-Adjustment-Programs-2023.pdf>

asking patients about accumulator programs and found that if patients are faced with a large, unexpected charge for a prescription drug, the top three reactions would be: abandoning or delaying their prescription fill; lengthening the time between doses; and asking their provider to switch to another drug.

SB 195 resolves this issue by simply ensuring that when calculating a patient's overall contribution to any out-of-pocket maximum or any cost-sharing requirement, a health plan must include any amounts paid by the patient or paid on behalf of the patient by another person.

The Arthritis Foundation thanks the committee for their consideration of SB 195 and urges all members to support this critical legislation.



Melissa Horn
Director of State Legislative Affairs
Arthritis Foundation
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Washington, D.C. 20036
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March 29, 2023

Colorado Senate Health and Human Services Committee
Colorado State Capitol - Room 357
200 East Colfax Avenue
Denver, CO 80203-1784

Re: SB 23-195 Copay Accumulator Ban Bill

Dear Members of the Senate Health and Human Services Committee:

On behalf of over 700 people with cystic fibrosis (CF) in Colorado, we write to express our support for SB 23-195, which would require insurers to apply third-party assistance to out-of-pocket maximums and other patient cost-sharing requirements. We recognize that copay assistance is problematic; it allows pharmaceutical companies to charge payers high prices, while shielding many individual patients from the costs. It is reasonable that payers would push back against this tactic, as drug costs continue to increase. Nevertheless, patients with chronic diseases like CF often struggle to afford their care and rely on copay assistance to access vital medications. SB 23-195 would help ensure patients' health and financial wellbeing are not sacrificed in the ongoing, systemic debate between payers and pharmaceutical companies about prescription drug pricing.

Cystic fibrosis is a life-threatening genetic disease that affects nearly 40,000 children and adults in the United States. CF causes the body to produce thick, sticky mucus that clogs the lungs and digestive system, which can lead to life-threatening infections. Cystic fibrosis is both serious and progressive; lung damage caused by infection is irreversible and can have a lasting impact on length and quality of life. As a complex, multi-system condition, CF requires targeted, specialized treatment and medications. While advances in CF care are helping people live longer, healthier lives, we also know that the cost of care is a barrier to care for many people with the disease.

Accumulator programs prevent third-party payments from counting towards deductibles and out-of-pocket limits and therefore increase out-of-pocket costs for patients—which can cause people with CF to forgo needed care and lead to adverse health outcomes. According to a survey conducted by George Washington University of over 1,800 people living with CF and their families, nearly half reported delaying or forgoing care—including skipping medication doses, taking less medicine than prescribed, delaying filling a prescription, or skipping a treatment altogether—due to cost concerns.¹ Because CF is a progressive disease, patients who delay or forgo treatment face increased risk of lung exacerbations, irreversible lung damage, and costly hospitalizations.

Accumulator programs also place additional financial strain on people with CF who are already struggling to afford their care. More than 70 percent of survey respondents indicated that paying for health care has caused financial problems such as being contacted by a collection agency, filing for bankruptcy, experiencing difficulty paying for basic living expenses like rent and utilities, or taking a second job to make ends meet. And while three quarters of people received some form of financial

¹ https://hsrc.himmelfarb.gwu.edu/cgi/viewcontent.cgi?article=1056&context=sphhs_policy_briefs

assistance in 2019 to pay for their health care, nearly half still reported problems paying for at least one CF medication or service in that same year.

We understand the challenge insurers face in managing the rising cost of drugs, and that copay assistance programs mask bigger cost and affordability issues in the health care system. However, cost containment strategies that further burden patients are unacceptable. Accumulators are especially challenging for a disease like CF, which has no generic options for many of the condition's vital therapies. The situation has become even more dire as a company that manufactures CF therapies recently reduced the amount of copay assistance available for people enrolled in accumulator programs.

We urge you to support SB 23-195 and help ensure continued access to quality, specialty care for people with CF. The Cystic Fibrosis Foundation appreciates your attention to this important issue for the CF community in Colorado.

Sincerely,

A handwritten signature in black ink, appearing to read "Mary B. Dwight". The signature is fluid and cursive, with a large initial "M" and "D".

Mary B. Dwight
Chief Policy & Advocacy Officer
Senior Vice President, Policy & Advocacy
Cystic Fibrosis Foundation

Gary R. Feldman, MD, FACR
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Joshua Stolow, MD
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HEADQUARTER OFFICE

Ann Marie Moss
Executive Director

March 29, 2023

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

Re: Support for SB 195

The Coalition of State Rheumatology Organizations (CSRO) is a national organization composed of over 30 state and regional professional rheumatology societies. CSRO was formed by physicians to ensure excellence and access to the highest quality care for patients with rheumatologic, autoimmune, and musculoskeletal disease. It is with this in mind that we write to you regarding SB 195.

As you consider SB 195, CSRO would like to convey its support for reforming the use of accumulator adjustment programs. SB 195 prevents double dipping by health insurers, and avoids serious health consequences for patients.

Rheumatologists are entrusted with the safe care of patients with rheumatoid arthritis and other autoimmune diseases that require the careful choice of safe and effective pharmaceutical and biological therapies. In many cases, this entails prescribing life changing, albeit expensive, drug therapies. Rheumatologists are very concerned with the financial impact that these therapies have on patients. Indeed, the increasingly untenable financial burden borne by patients with musculoskeletal illnesses, particularly those with autoimmune conditions, has had undeniable consequences for therapy adherence and ultimate patient outcomes.

Patients utilizing specialty drugs have likely already tried and failed all the available lower cost alternatives, but the drug they need is still out of reach. This is because their co-insurances can be greater than \$1000 a month. Consequently, many would go without treatment if it weren't for patient assistance through co-pay cards. Many patients requiring these co-pay cards for their specialty medicines often have chronic diseases with multiple co-morbidities and medications. As a result, they cannot afford high premiums and are forced into policies with high deductibles that can be thousands of dollars.

Until recently, co-pay assistance counted towards a patient's deductible, and the health plan would collect the value of the deductible regardless of who paid. However, several years ago, insurers and pharmacy benefit managers began using alternative cost-sharing structures known as "accumulator adjustment programs." These programs prevent the value of co-pay assistance from being applied towards a patient's deductible as an out-of-pocket expense.

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Under these programs, **insurers will pocket the value of the co-pay card in addition to demanding the full deductible value from the patient.** This is despite the fact that patients utilizing these drugs already pay co-insurance based on the list price of the drug rather than the discounted price the PBM or health plan receives.

As stated earlier, due to the move towards high deductible health plans, and the inherent costliness of the drugs used to treat complex chronic conditions, most patients will not be able to afford their medication once the co-pay card benefit is exhausted and they are then forced to start paying off their deductible. This is despite the fact that the plan had already received the deductible amount or more from the co-pay card.

This will result in otherwise stable patients discontinuing their treatments, allowing for irreversible disease progression, flares, loss of effectiveness of their original therapy, and other adverse effects. Managing these results from non-adherence requires the use of substantially more resources than allowing for continuity of care from the beginning.

Stabilizing a patient's inflammatory condition, such as rheumatoid arthritis and lupus, is a process that can take months or even years of trial and error, based on disease complexity, the patient's unique medical history, and the clinical characteristics of the drugs being used. Rheumatologists do not prescribe expensive medications idly. Expensive medications are prescribed because they are medically necessary.

The use of accumulator programs by health plans and PBMs has been instituted without regard to the fact that most patients have no other choice than to use an expensive medicine for chronic diseases that impact every part of their lives. Indeed, it is patients with chronic diseases requiring lifelong treatments, often already experiencing disparity in health care, that are affected most by this unfair and discriminatory practice.

According to research done by IQVIA, co-pay card use for branded drugs that have lost exclusivity or have generic equivalents, "... represents a sliver of the total commercial market, making up only 0.4% of volume across all products." And only 3.4% of the total commercial volume has prescriptions that use co-pay cards.¹

We urge you to support this legislation, which prevents insurers from discriminatorily punishing patients with complex chronic conditions when they

¹AN EVALUATION OF CO-PAY CARD UTILIZATION IN BRANDS AFTER GENERIC COMPETITOR LAUNCH, IQVIA, <https://www.iqvia.com/-/media/iqvia/pdfs/us/us-location-site/market-access/fact-sheet-evaluation-of-copay-card-utilization-post-loe.pdf?& =1620140157792>

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use accumulator programs to collect multiple deductibles from the assistance programs and the patients themselves.

For these reasons we request your support for SB 195.

Respectfully,



Gary Feldman, MD, FACR
President
Board of Directors



Madelaine A. Feldman, MD, FACR
VP, Advocacy & Government Affairs
Board of Directors



March 30, 2023

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

Re: S.B. 23-195 *Calculation of Contributions to Meet Cost Sharing*

On behalf of the EveryLife Foundation for Rare Diseases, we are pleased to submit testimony in support of S.B. 23-195, *Calculation of Contributions to Meet Cost Sharing*. The EveryLife Foundation is a nonprofit, nonpartisan organization dedicated to empowering the rare disease patient community to advocate for impactful, science-driven legislation and policy that advances the equitable development of and access to lifesaving diagnoses, treatments, and cures.

It is estimated that over 30 million Americans live with one or more rare diseases that often result in burdensome medical, indirect, and non-medical expenses. Patients and families must navigate how to manage expenses from multiple inpatient and outpatient encounters, costs for prescription therapies and medical devices, and the support services that are critical for managing their health and well-being.

While 95% of rare diseases do not yet have an FDA-approved treatment, for those patients who do have an available therapy, cost-sharing assistance from drug manufacturers and patient assistance programs is an important factor in the ability to access life-altering and life-saving treatments. Unfortunately, insurance companies are increasingly employing accumulator adjustment programs that prevent cost-sharing assistance from being applied to a patient's deductible or out-of-pocket maximum, removing the lifeline of cost-sharing assistance programs. In Colorado, 25-50% of ACA health plans have copay accumulator policies.¹ SB 23-195 would prevent insurers from using these programs to take advantage of Colorado residents.

While copay accumulator programs can reduce costs for insurance companies, they leave patients with unexpected and unaffordable costs once their copay assistance is exhausted. In 2022, the EveryLife Foundation published *The National Economic Burden of Rare Diseases in the United States*, a study that examined the comprehensive economic impact of a subset of 379 rare diseases. The study found that the total economic impact of rare diseases in the US in 2019 was \$997 billion; 60% of those costs were indirect and non-medical costs shouldered directly by families and society. Of the direct costs, inpatient care was the top driver of medical costs (~15%) while prescription medication was responsible for about 11% of medical costs.² Lowering the costs of health care is an important goal; however, insurance companies that use

¹ The Aids Institute. February 2023. [Discriminatory Copay Policies Undermine Coverage for People with Chronic Illness](#).

² EveryLife Foundation for Rare Diseases. April 2022. [The National Economic Burden of Rare Disease in the United States in 2019](#).

copay adjustment programs simply shift costs to patients while ultimately collecting up to double the amount of the patient's out-of-pocket requirements. Further exacerbating the tremendous out-of-pocket financial load families living with rare diseases are expected to bear.

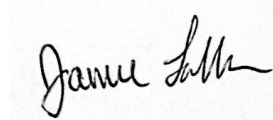
Copay accumulator programs eat into the already tight budget patients have, forcing some patients to take harmful actions, such as medicine rationing and prescription abandonment. An analysis by IQVIA showed that when patient costs reach \$250, over 70% of new patients walk away from the pharmacy empty-handed, highlighting the direct connection between the rise in out-of-pocket costs and prescription abandonment.³

Prescription abandonment is not an option for rare disease patients who are forced to incur considerable financial strain to maintain their prescription medicine costs. Additionally, with the proliferation of high deductible health plans, copay accumulator programs can result in higher out-of-pocket costs for the frequent expert outpatient care that rare disease patients require as it takes longer for patients to satisfy the deductible and out-of-pocket maximum requirements.

Thank you again for the opportunity to testify in support of S.B. 23-195. We are excited at the prospect of Colorado joining the other sixteen states that have enacted similar legislation to protect patient access to treatments by preventing accumulator adjustment programs. We readily support Senator Winter, Senator Will, Representative Jodeh, and Representative Pugliese for taking a lead on this issue to ensure that all Colorado residents with a rare disease can maintain access to affordable, life-sustaining medical care.



Emily Stauffer
State Policy Manager
EveryLife Foundation for Rare Diseases



Jamie Sullivan
Senior Director of Policy
EveryLife Foundation for Rare Diseases

CC:

Annie Kennedy, Chief of Policy, Advocacy and Patient Engagement, EveryLife Foundation
Julia Jenkins, Executive Director, EveryLife Foundation
Frank Sasinowski, Chair of the Board, EveryLife Foundation

³ IQVIA. May 2019. [Medicine Use and Spending in the US; A Review of 2018 outlook to 2023.](#)

Thank you.

My name is Nathan Wilkes and I live in Arapahoe County with my wife and children.

I come to you in support of SB23-195 for many reasons, both personal and pragmatic.

Our family's medical bills typically exceed \$1 million per year, almost all of that from a drug used to treat a chronic, life-threatening condition. It has been that way for us since 2003.

Before the ACA, we fought against many unfair practices that insurers and providers were using to extract maximum profit from patients. Blanket denials, pre-authorizations, lifetime caps, and more.

The ACA started to fix some problems, and additional state laws since then have done so much more.

However, we're dealing with **insurance contracts** with language that is unclear. We constantly get bills we don't know if we're supposed to pay. The whole system is confusing and stacked against the patients.

A few years back, we were doing what we normally do every January 2nd. We fill a monthly prescription, picking up 5 small vials in a Ziploc bag whose total cost at the pharmacy counter is \$75,000. He tells us our payment will be the \$5,000 deductible plus another \$2,000 in coinsurance and we share an uneasy laugh about that, both knowing this is ridiculous. He ticks a box on his screen to allow us to take the life-saving medication without having to cough up such a large sum. He's a pharmacist, not an extortionist.

Our pharmacy bill progresses through insurance and we get a statement in the mail soon after. After a dozen years of fighting an industry that never helps us and doesn't need to exist, we fall into familiar routines of delaying bill payment. The prior year, we had used a drug manufacturer's copay assistance program to cover the initial cost of the drug that would otherwise make it unaffordable and therefore unobtainable.

We put off filing the copay assistance paperwork for this Rx fill a bit longer than anticipated. I soon got a call from the insurer, asking when we would be paying our bill, and specifically **IF COPAY ASSISTANCE** was going to be used. The agent was very insistent on getting it booked as soon as possible. This caught my attention, so I did some digging and discovered that accumulator adjustors could be at play.

I even asked some of my friends at DOI and searched SERFF filings to see how prevalent these new Accumulator Adjustor "innovations" were. They had no idea, it wasn't tracked, and they weren't even sure if they could regulate it even if they could see it.

Knowing this, we delayed our copay assistance payment until after our December fill so our insurer wouldn't have time to hit us with one.

I'm an engineer. Numbers and formulas are my life. I took to explore what an accumulator adjustor would do to our experience. The resulting formulas are complex and confusing, because they have to account for deductibles, coinsurance, OOP maximums and more for every calculation. If you want to find extreme waste in health care, here it is. Bean counters aren't health care providers.

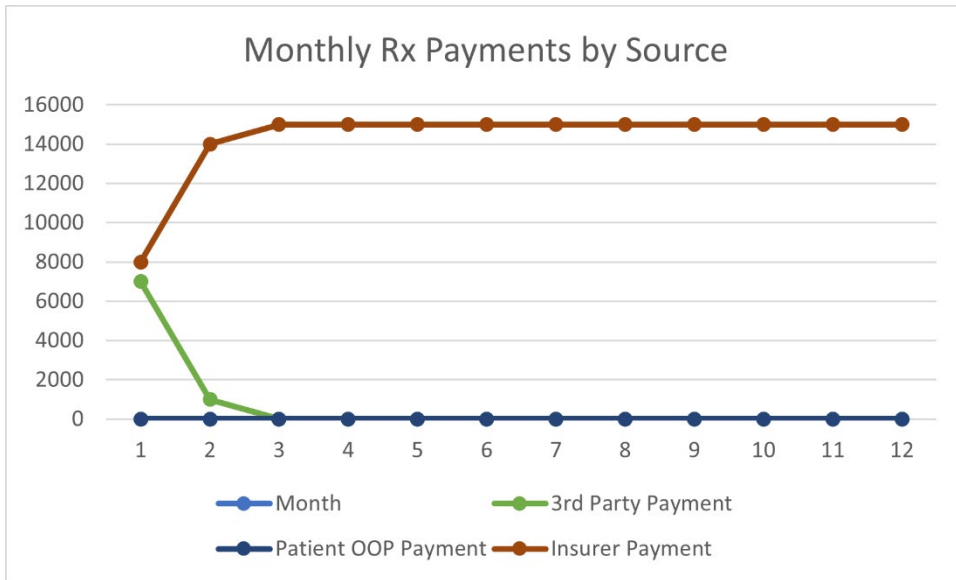
But the results are clear. Without accumulators, the insurer reduces their payment responsibility by the total amount paid. With accumulators, the insurer gets to soak the patient AGAIN for the same amount, effectively doubling their profit.

Nathan Wilkes
Arapahoe County

In a hypothetical scenario:

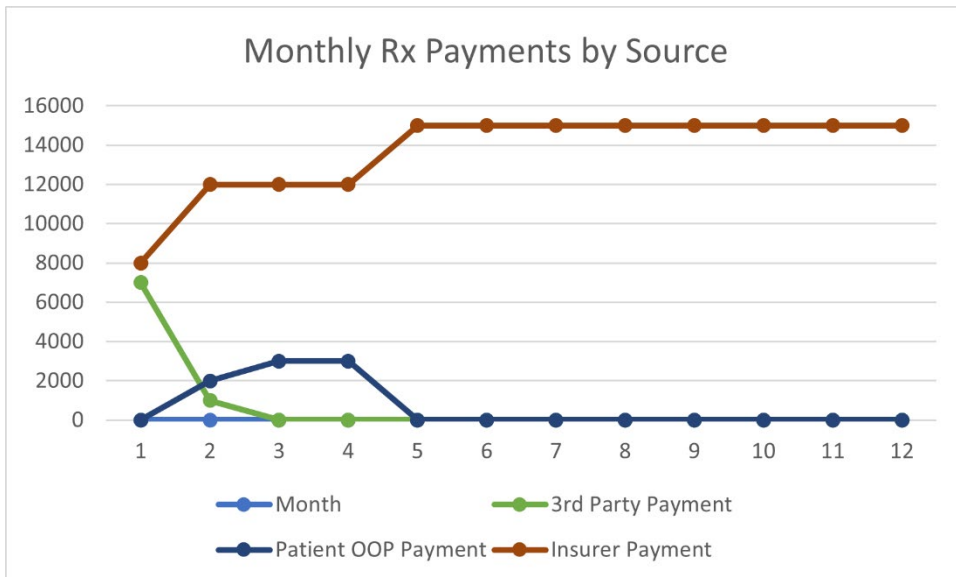
Monthly Drug Cost	\$15,000
Deductible	\$5,000
Out-Of-Pocket Maximum	\$8,000
Coinsurance Percentage	20%
Copay Assistance Maximum	\$8,000

Without Accumulator Adjustor



PROFIT to INSURER = \$8,000 (Sum of all non-insurer payments)

WITH Accumulator Adjustor



PROFIT to INSURER = \$16,000 (Sum of all non-insurer payments)

This egregious double-dipping should be enough to outlaw the practice, but I would like you to also consider the purpose of out-of-pocket payments in the first place.

I've heard that patients must "feel the heat" for medical bills, as if they were somehow personally responsible for their own illness and need to be punished.

I've heard that we must do this to allow "market forces" to work, but there is no market force that is going to allow patients to bring down the price of \$10,000 drugs at the pharmacy counter. We are over a barrel.

The bottom line is that **any** medical bill will get in between a patient and the care that they need. For the most expensive drugs, this means either catastrophic medical debt or no medication at all.

We don't need to foster that environment, especially while giving insurers a **green light to double-dip** their own policyholders **for pure profit**.

If this practice is not outlawed, then you are telling the citizens of Colorado that sick people must continue to be economically punished for their illnesses and that insurer profits are our top priority.

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March 30, 2023

Senator Rhonda Fields, Chair
Senate Health and Human Services Committee
Colorado General Assembly
200 E Colfax Avenue
Denver, CO 80203

Dear Chair Fields and Members of the Senate Health and Human Services Committee,

The Rocky Mountain Oncology Society (RMOS) and the Association for Clinical Oncology (ASCO) are pleased to support SB 195, which would take steps to protect patients with cancer in Colorado from copay accumulator programs.

Formed in 1991, RMOS is a diverse community of oncology professionals whose mission is to promote the highest professional standards of oncology, research and exchange information and ideas leading to improvements in oncology. ASCO is the world's leading professional society representing physicians who care for people with cancer. With nearly 45,000 members, our core mission is to ensure that patients with cancer have meaningful access to high quality, equitable cancer care.

RMOS and ASCO are committed to supporting policies that reduce cost while preserving quality of cancer care; however, it is critical that such policies be developed and implemented in a way that does not undermine patient access. Copay accumulator programs target specialty drugs for which manufacturers often provide copay assistance. With a co-pay accumulator program in place, a manufacturer's assistance no longer applies toward a patient's co-pay or out-of-pocket maximum. This policy means patients will experience increased out of pocket costs and take longer to reach required deductibles. By prohibiting these funds from counting toward patient premiums and deductibles, co-pay accumulators negate the intended benefit of patient assistance programs and remove a safety net for patients who need expensive specialty medications but cannot afford them.

Copay accumulator programs lack transparency and are often implemented without a patient's knowledge or full understanding of their new "benefit." Far from being beneficial, copay accumulator programs increase financial burden for patients, many of whom are facing life-threatening illness. The impact is especially hard on low-income populations. Increasing patient cost can contribute to medical bankruptcy and cause patients to discontinue care, seek non-medical alternatives—or forego treatment altogether. The result is poorer health outcomes and greater cost to the system.

RMOS and ASCO are encouraged by the steps that SB 195 takes toward eliminating co-pay accumulator programs in Colorado, and we strongly urge the House to pass the measure. For a more detailed understanding of our policy recommendations on this issue, we invite you to read the [ASCO Policy Brief on Co-Pay Accumulators](#) by our affiliate, the American Society of Clinical Oncology.

We welcome the opportunity to be a resource for you. Please contact Aaron Segel at ASCO aaron.segel@asco.org if you have any questions or if we can be of assistance.

Sincerely,

Tejas Patil, MD
President
Rocky Mountain Oncology Society

Lori J. Pierce, MD, FASTRO, FASCO
Chair of the Board
Association for Clinical Oncology



March 29, 2023

Senate Health and Human Services Committee
Colorado State Senate
200 E. Colfax Rm 346
Denver, CO 80203

RE: SB 23-195 - Support

Dear Members of the Senate Health and Human Services Committee,

On behalf of the International Foundation for Autoimmune & Autoinflammatory Arthritis (AIArthritis), I encourage you to support SB 23-195 when it is in your committee.

We are leaders in advancing education, advocacy, and research for those impacted by autoimmune and autoinflammatory arthritis (AIArthritis) diseases through peer-led guidance, collaboration, and resources that are driven by patient-identified issues and patient-infused solutions. As we are led by patients we understand the importance of ensuring that all copays made by or on behalf of a patient are counted toward that patient's deductible and out-of-pocket maximum.

Those living with AIArthritis diseases already face higher-than-average healthcare costs, and our medications are often far costlier than medications for other conditions, and often have few or no alternatives. Because our medications are so expensive - **sometimes having copays in the thousands of dollars** - we rely on copay assistance programs to help us afford them. When these assistance programs aren't counted toward our deductible and out-of-pocket maximums, many of us are forced to forgo the medication, or make a choice to forgo another medical treatment later in the year. When AIArthritis patients miss treatments or medications, many will develop comorbidities due to uncontrolled inflammation. **This not only causes pain and suffering for the patient, but increases health care consumption and costs for both the person affected and the health system as a whole.**

SB 23-195 will help ease this burden, by making sure that all copays are counted.

We urge you to continue to protect patients in Colorado by supporting SB 23-195.

Sincerely,

Lindsey Viscarra
Public Policy Manager
International Foundation for Autoimmune & Autoinflammatory Arthritis

Archived: Tuesday, June 13, 2023 1:53:51 PM
From: Mark Weston
Sent: Thu, 30 Mar 2023 12:49:18 -0600
Subject: SB23-195

Dear Jerard Brown,

Please distribute this letter in support of the captioned bill to the leadership and members of the Senate Health & Human Services Committee.

I am a Lakewood voter with amyotrophic lateral sclerosis (ALS, or Lou Gehrig's disease). ALS is invariably fatal and has no cure, but the progression of some of its symptoms can be slowed if one is lucky enough to have access to one or more very expensive specialized prescription medications. Accordingly, I spend a lot of my time shopping for the best prices on a number of these drugs.

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I am reasonably well-informed, educated, and still know that I'm caught in a three-dimensional web where only the insurance companies know the rules. I pay three different monthly insurance premiums for three separate but related health insurance plans. Between Medicare Part D, online GoodRx coupons, and my traditional Medicare Part B coverage (supplemented with a pricey private medigap policy), trying to understand and control costs is a major undertaking. This applies specifically to the deductibles and co-pays, different for prescription medications and regular doctor visits. =C2=A0

SB23-195 as introduced will ensure that any payment made by or on behalf of a "covered person" is counted in the calculation of their contributions toward cost-sharing requirements. This legislation will reinforce the benefit of copay assistance programs and ensure access to life-saving (for some at least), high-cost medicines that do not have generic alternatives, or for which generic alternatives remain prohibitively expensive. I understand that similar legislation has already been passed in 16 other states, each, like the FN for this bill, with minimal to no fiscal notes, and with no noteworthy impact to insurance premium costs. =C2=A0

All Coloradans should be able to afford their prescribed medications, which is why I encourage all members to vote yes on SB23-195 in today's Health and Human Services Committee hearing. =

Thank you.

**Mark Weston
Director, Colorado Division of Conservation (retired)
1699 Taft St, Lakewood 80215
(303) 898-0244**