



MISSOURI HOUSE OF REPRESENTATIVES
WITNESS APPEARANCE FORM

BILL NUMBER: HB 1628		DATE: 2/26/2024	
COMMITTEE: Health and Mental Health Policy			
TESTIFYING: <input checked="" type="checkbox"/> IN SUPPORT OF <input type="checkbox"/> IN OPPOSITION TO <input type="checkbox"/> FOR INFORMATIONAL PURPOSES			
WITNESS NAME			
BUSINESS/ORGANIZATION:			
WITNESS NAME: AARON SEGEL		PHONE NUMBER: 617-548-2762	
BUSINESS/ORGANIZATION NAME: MISSOURI ONCOLOGY SOCIETY (MOS)/ASSOCIATION FOR CLINICAL ONCOLOGY (ASCO)		TITLE:	
ADDRESS: 2318 OLD MILL RD, SUITE 800			
CITY: ALEXANDRIA		STATE: VA	ZIP: 20001
EMAIL: aaron.segel@asco.org	ATTENDANCE: Written	SUBMIT DATE: 2/23/2024 11:51 AM	

THE INFORMATION ON THIS FORM IS PUBLIC RECORD UNDER CHAPTER 610, RSMo.

Dear Chair Stephens and Members of the House Committee on Health and Mental Health Policy, The Missouri Oncology Society (MOS) and the Association for Clinical Oncology (ASCO) write to support HB 1628, which would prohibit health carriers in the state from utilizing co-pay accumulator programs and save patients with cancer on their out-of-pocket costs. The Missouri Oncology Society (MOS) is a community of oncologists, nurse practitioners, physician assistants, and other allied health professionals who provide a powerful voice for multidisciplinary cancer care teams and the patients they serve. ASCO is a national organization representing physicians who care for people with cancer. With nearly 50,000 members, our core mission is to ensure that cancer patients have meaningful access to high-quality, equitable cancer care. MOS 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. Co-pay accumulator programs target specialty drugs for which manufacturers often provide co-pay 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. Co-pay accumulator programs lack transparency and are often implemented without a patient's knowledge or full understanding of their new "benefit." Far from being beneficial, co-pay 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. MOS and ASCO are encouraged by the steps HB 1628 takes toward eliminating co-pay accumulator programs in Missouri and we strongly urge the House Committee on Health and Mental Health Policy to pass it. 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](mailto:ASCO.aaron.segel@asco.org) if you have any questions or if we can be of assistance. Sincerely,



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WITNESS NAME		
REGISTERED LOBBYIST:		
WITNESS NAME: ANNA MEYER		PHONE NUMBER: 573-823-6533
REPRESENTING: NATIONAL MULTIPLE SCLEROSIS SOCIETY		TITLE:
ADDRESS: 10420 OLD OLIVE STREET BLVD.		
CITY: ST. LOUIS		STATE: MO
		ZIP: 63141
EMAIL:	ATTENDANCE:	SUBMIT DATE: 2/26/2024 12:00 AM
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WITNESS NAME		
INDIVIDUAL:		
WITNESS NAME: ARNIE C. "HONEST-ABE" DIENOFF-STATE PUBLIC ADVOCATE		PHONE NUMBER:
BUSINESS/ORGANIZATION NAME:		TITLE:
ADDRESS:		
CITY:		STATE: ZIP:
EMAIL: arniedienoff@yahoo.com	ATTENDANCE: Written	SUBMIT DATE: 2/26/2024 10:27 PM

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I am in Support o this Bill. The Cost of a Name-Brand Drug shall be in the Calculation of the Deductible, where a Generic Drug is NOT available. This is Common-Sense Legislation.



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WITNESS NAME			
INDIVIDUAL:			
WITNESS NAME: ASHLEY PALMER		PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:		TITLE:	
ADDRESS:			
CITY:		STATE:	ZIP:
EMAIL: ashleypalmercota@gmail.com	ATTENDANCE: Written		SUBMIT DATE: 2/26/2024 8:42 AM
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I am a person who has been diagnosed with a chronic condition (inflammatory arthritis) that is only adequately treated with expensive, injectable medications. I am in my late 20 and have a growing family. My medication allows me to continue living my life as I need to, allowing me to stay active and support my family. There are no alternative treatments that are cheaper. In order to obtain a prescription to get this medication I am required to do frequent scans, bloodwork, specialists visits and other cost prohibitive medical things. These costs add up and are only compounded by the cost of the medication once approved. The only way I can afford my medication on top of my other medical needs is manufacturer copay assistance, as my medical insurance along with most others, deems my medication "not medically necessary" despite the fact that without it I will become physically incapacitated and unable to participate in daily life. I used to work in a state where copay accumulators were banned and upon filling my medication the copay assistance counted toward my deductible and out of pocket maximum, easing the financial burden and length of time it took to reach the point that my insurance would cover my medication. When I moved to Missouri and my new insurance kicked in, I quickly realized I faced a new reality: my insurance would not cover my medication and my copay assistance would not be utilized to help me reach the point that it would help me financially. This is because my insurance plan (and over 90% of those in Missouri) allow copay accumulator riders that prohibit any money paid toward your copay by someone other than yourself to count. I now rely on other means to afford my medication, but it is a fight to get my medication filled each month. Please consider pushing this bill through for the patients like myself. We did not ask for these conditions. We do not like having to fight with insurance and struggle to afford medication, sometimes choosing between treatment or other basic necessities. Please help people like me who just want to live our lives on the same level as everyone else, while also being able to afford what we need.



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WITNESS NAME		
BUSINESS/ORGANIZATION:		
WITNESS NAME: BRIDGET TYREY		PHONE NUMBER: 314-482-5973
BUSINESS/ORGANIZATION NAME: GATEWAY HEMOPHILIA ASSOCIATION		TITLE: EXECUTIVE DIRECTOR
ADDRESS: 4976 EICHELBERGER STREET		
CITY: ST. LOUIS		STATE: MO
		ZIP: 63109
EMAIL:	ATTENDANCE:	SUBMIT DATE: 2/26/2024 12:00 AM
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WITNESS NAME			
BUSINESS/ORGANIZATION:			
WITNESS NAME: EMILY KALMER		PHONE NUMBER: 314-455-8657	
BUSINESS/ORGANIZATION NAME: AMERICAN CANCER SOCIETY-CANCER ACTION NETWORK		TITLE: MISSOURI GOVERNMENT RELATIONS DIRECTOR	
ADDRESS: 1001 CRAIG RD.			
CITY: ST. LOUIS		STATE: MO	ZIP: 63146
EMAIL:	ATTENDANCE:	SUBMIT DATE: 2/26/2024 12:00 AM	
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WITNESS NAME			
INDIVIDUAL:			
WITNESS NAME: JACKIE GLASCOCK		PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:		TITLE:	
ADDRESS:			
CITY:		STATE:	ZIP:
EMAIL:	ATTENDANCE:		SUBMIT DATE: 2/26/2024 12:00 AM
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WITNESS NAME			
INDIVIDUAL:			
WITNESS NAME: JOAN GUMMELS		PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:		TITLE:	
ADDRESS:			
CITY:		STATE:	ZIP:
EMAIL: jfgummels@gmail.com		ATTENDANCE: Written	SUBMIT DATE: 2/25/2024 7:55 PM

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Mr. Chairman and Members of the Committee: My name is Joan Gummels. I write in support of HB 1628 to ensure that all co-payments made on behalf of an insurance enrollee count towards that patient's out-of-pocket maximum. For Missourians living with chronic, incurable illness, "buying time" isn't just a turn of phrase. Often life-extending medications are cutting-edge and expensive. I am currently in treatment for metastatic ovarian cancer, inoperable and incurable, but so far treatable. Prior to the current course of chemotherapy, I enjoyed a year of stable disease, using a relatively new oral medication for maintenance. Recent developments have expanded treatment options for ovarian cancer. In the last decade, the FDA has approved more new treatments than in the previous four decades combined. These medications are typically considered specialty medications, with no generics available for many years. Like many cancer patients on expensive medications, I sought out and used a patient assistance program. I was extremely surprised to find that although my insurance company received the full extent of co-payments it expected, these amounts were not credited to me in terms of my out-of-pocket maximum – meaning, I would have to pay the company the same amount AGAIN in order to meet the maximum. Requiring that all co-payments made on behalf of enrollees count toward their out-of-pocket maximum ensures that the provider still receives that maximum to which it entitled while lifting an economic burden on Missourians living with serous chronic conditions. I respectfully request that you support HB 1628 and vote it out of committee for consideration by the House. Thank you for your time today and attention to this important issue.



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WITNESS NAME		
REGISTERED LOBBYIST:		
WITNESS NAME: JORGEN SCHLEMEIER		PHONE NUMBER: 573-634-4876
REPRESENTING: MISSOURI PHARMACY ASSOCIATION		TITLE:
ADDRESS: 213 E. CAPITOL AVE.		
CITY: JEFFERSON CITY		STATE: MO
		ZIP: 65101
EMAIL:	ATTENDANCE:	SUBMIT DATE: 2/26/2024 12:00 AM
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WITNESS NAME			
REGISTERED LOBBYIST:			
WITNESS NAME: MADISON EACRET		PHONE NUMBER: 314-882-1007	
REPRESENTING: ALS ASSOCIATION		TITLE: GOVERNMENT AFFAIRS ASSOCIATE	
ADDRESS: 124 E HIGH STREET			
CITY: JEFFERSON CITY		STATE: MO	ZIP: 65101
EMAIL: madison@penman.group	ATTENDANCE: Written	SUBMIT DATE: 2/26/2024 12:21 PM	
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On behalf of all Missourians living with ALS, including the over 500 people we serve each year in Missouri, we respectfully request your support for H.B. 1628, which will significantly help reduce the out-of-pocket healthcare costs for our community. Amyotrophic lateral sclerosis (ALS) is a fatal progressive neurodegenerative disease that slowly robs a person's ability to walk, talk, eat, and eventually breathe. The cost of care for someone living with ALS is astronomical, with annual out-of-pocket expenses reaching upwards of \$250,000 per year. As with many people living with complex medical conditions, those with ALS must take various drugs to maintain their health. The copays associated with acquiring them significantly add to this crushing financial burden. One way that people with ALS afford their care is through copay assistance programs, where cards or coupons from nonprofit organizations or drug manufacturers help reduce the cost of drugs. However, insurers and pharmacy benefit managers increasingly use copay accumulator adjustment programs to prevent such assistance from counting towards patient cost-sharing, such as their deductible or annual out-of-pocket maximum. In effect, the insurer is paid twice by demanding payment of out-of-pocket costs: first from copay assistance programs and then again from patients. Copay accumulator adjustment programs do not just harm patients' finances; they undermine their access to life-saving prescription drugs, making it even more difficult for people living with ALS and other complex medical conditions to adhere to a treatment plan. With lower copays, consumers are more likely to take their medications regularly. We strongly support the prohibition of copay accumulator adjustment programs. We believe that all Missourians should be able to afford necessary treatments by ensuring all payments – made by or on behalf of them – are counted towards their deductible and out-of-pocket maximums. Thank you for your time and your consideration of this critical legislation. For all these reasons, we respectfully request your support for H.B. 1628.



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WITNESS NAME		
INDIVIDUAL:		
WITNESS NAME: MARK S. BOX, MD		PHONE NUMBER:
BUSINESS/ORGANIZATION NAME:		TITLE:
ADDRESS:		
CITY:		STATE: ZIP:
EMAIL:	ATTENDANCE:	SUBMIT DATE: 2/26/2024 12:00 AM
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WITNESS NAME			
INDIVIDUAL:			
WITNESS NAME: MEGAN LARSEN		PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:		TITLE:	
ADDRESS:			
CITY:		STATE:	ZIP:
EMAIL: nesralmegan@gmail.com	ATTENDANCE: In-Person	SUBMIT DATE: 2/26/2024 1:01 AM	
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I would like to read this in person-Senate Bill 844 and House Bill 1628 would require healthcare insurance companies to accept all copay assistance payments toward patient deductibles and out-of-pocket maximums in Missouri. This is the fourth legislative session in a row that supporters are seeking to get a bill passed.-First, let me thank the members for introducing this bill to reign in not only the Pharmacy Benefit Managers and their Pharma counter partsSo, let me start with my history so you can see what has led me here today and why I do what I do, as it relates to this bill and also dispel any causal fallacy arguments I have heard from varying Pharmaceutical CEOs in the past few weeks. Full disclosure, I am a cold war kid and my choices in media and story telling will reflect this.Let's go back in time.I was born on an airbase in Northern Japan, in 1986. If you were around in the mid 80's, you would understand the importance of this airbase placed quite strategically near Kamchatka-Krai and Sakhalin Island. I am the now adult daughter of someone who worked with Naval Intelligence, as a russian linguist. Because of his position, I was afforded at the time, Champus healthcare. When I was around two years old we had moved to a tiny town in the North East of Scotland's grey rocky coast. Suddenly, I get sick. My parents took me to the doctor to get bloodwork and it was confirmed via Bethesda Naval Hospital I had Juvenile Rheumatoid Arthritis. Two months later I was on, ironically, Pan Am flight 103, two weeks before its fatal trip over Lockerbie Scotland. For years, while dad was somewhere in the North Atlantic, my mom was making sure Champus would cover whatever care I needed. Whenever I write down my history, I think of Dr Manhattan from the watchmen. While he is sitting on Mars away from humanity, he is simultaneously in multiple years at once. I feel the same way explaining the rocketing pharmaceutical nightmare that keeps devastating the working class. It never ends.When I was twelve, at this point Champus was about to become Tricare. At the very same time, Enbrel comes out and while tricare does cover this new biologic drug something is bubbling underneath the surface. This is 1998.Pharmaceutical companies are starting to understand they can charge abhorrent amounts for this drug, and also reward co pay assistance cards to those in certain income brackets. By the time I had aged out of Tricare in 2007, the insurance companies were starting to manipulate their customers even more by saying you can't be on this drug and if you are we will only give you a six month co pay card. At this point, I'm discovering corporate America does not have the same coverage as Tricare. I get a new plan through whichever huge company i work for in St Louis. Suddenly co pay cards and co pay accumulators are a thing. The money from the co pay card never went onto my deductible and at this point I would have had to pay hundreds or thousands of dollars for a medication that keeps my white blood cells from eating my cartilage.Jumping forward now to 2023/2024 I am on Medicare. I went to Washington DC this past year to speak to various reps about this sort of legislation. And now I am here because in the past week I have heard the following.When asked about the soaring costs of drugs, the pharmaceutical CEOs have said things such as, "The cost of the drug in America is higher than outside the US because of the value the customer receives, or, they

can't drop the cost of the drugs because it will delay their development."If that was truly the case then why did I watch drug costs soar across a 25 year period. The drug had the same value to me at age twelve as it does now, except now the cost is abhorrent. And as far as not being able to drop the cost of these drugs due to a notion that research would suddenly stop, is absurd. Especially if you take into consideration most of the positive medical changes that have happened in the United States are because of funding given to Universities or military adjacent facilities. I would know. I was one of the kids who received a zoster shot, multiple times to prove its efficacy within the walls of Bethesda prior to it being released. There is no proof that lowering these costs would make other customers of these insurance plans shoulder the burden. What has been proven over and over is the lower and middle class people cannot afford their medications for either themselves or their families. The same is glaringly obvious with active and retired military families. To wrap things up I do want to point out to my local reps, I have lived in St Louis, MO on and off my whole life. Just North West of STL city proper there's an area called Cold Water Creek. After the Manhattan project was complete, the left over waste from refining uranium in the area ended up seeping into the water and surrounding topography. Those people have been waiting a long time for relief. The monetary relief would help but so would this bill. It would adjust their deductibles for life saving medication without going bankrupt. I am not an anomaly, I just happen to have touched the military and corporate sector and have a better understanding because of how long I've been in the medical system. I was way healthier and had less visible damage prior to accumulators coming about. In fact if this system hadn't been utterly useless, I probably would still be working. To liken this to a political idea, this situation is similar to the US handing aid to a foreign country and saying oh just kidding this is going back into our pockets, so nothing benefits the other country. It is time that accumulators got Swan Laked, and disappeared, thank you.



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WITNESS NAME			
REGISTERED LOBBYIST:			
WITNESS NAME: MELISSA		PHONE NUMBER: 240-468-7464	
REPRESENTING: ARTHRITIS FOUNDATION		TITLE: DIRECTOR OF STATE LEGISLATIVE AFFAIRS	
ADDRESS: 1615 L ST. NW SUITE 320			
CITY: WASHINGTON		STATE: DC	ZIP: 20036
EMAIL: mhorn@arthritis.org	ATTENDANCE: Written	SUBMIT DATE: 2/26/2024 9:55 AM	

THE INFORMATION ON THIS FORM IS PUBLIC RECORD UNDER CHAPTER 610, RSMo.

Chair Stephens and Members of the Committee, On behalf of more than 1 million Missouri residents with doctor-diagnosed arthritis, thank you for the opportunity to submit testimony in support of HB 1628, which addresses cost-sharing requirements and copay accumulator adjustment programs. Copay accumulator 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 Missouri 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 Missouri State Legislature to act given 8 out of the 10 insurers in the state have an accumulator adjustment program. This impacts patient coverage for nearly 80% of marketplace plans! 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 filling 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 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. HB 1628 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 or third party. The Arthritis Foundation thanks the committee for their consideration of HB 1628 and urges all members to support this critical legislation. Melissa Horn, Director of State Legislative Affairs, Arthritis Foundation, 1615 L St. NW Suite 320, Washington, D.C. 20036, 240.468.7464



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WITNESS NAME		
INDIVIDUAL:		
WITNESS NAME: MICHAEL		PHONE NUMBER:
BUSINESS/ORGANIZATION NAME:		TITLE:
ADDRESS:		
CITY:		STATE: ZIP:
EMAIL: MichaelWesten.3up@protonmail.com	ATTENDANCE: Written	SUBMIT DATE: 2/26/2024 2:41 PM
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I SUPPORT HB 1628 as originally drafted.



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WITNESS NAME			
INDIVIDUAL:			
WITNESS NAME: NATHANIEL BROWN		PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:		TITLE:	
ADDRESS:			
CITY:		STATE:	ZIP:
EMAIL: nathaniel@chronicdiseasecoalition.org	ATTENDANCE: Written		SUBMIT DATE: 2/22/2024 4:36 PM

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On behalf of the Chronic Disease Coalition, thank you for the opportunity to provide support for HB 1628, which would address harmful copay accumulator programs that impact thousands of Missouri patients. 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 are pleased to support this legislation, which would ensure that all payments, including those by third parties, count toward insured Missourians' total cost-sharing requirements. Many chronic disease patients and their families rely on various types of copay assistance to afford the medications they need to manage their conditions. Unfortunately, insurers continue implement programs that limit all third-party copay assistance – real dollars paid to the insurer – from counting towards patients' out-of-pocket costs. This forces chronic disease patients to pay twice (or more), while dissuading needed charitable assistance for future patients. Many pharmaceutical manufacturers support patient assistance programs by providing funds for what are commonly known as copay coupons or manufacturer copay cards. Previously, payments using funds from these programs counted towards a patient's deductible, helping them afford coverage until the copay assistance is utilized and the benefits from insurance coverage begin. Copay accumulator programs or accumulator adjustment programs maximize the use of copay assistance without assisting in the patient's deductible, leaving chronic disease patients with exorbitant out-of-pocket costs on top of the many other challenges that come with their diagnoses. As health care leaders in Missouri, we urge you to join the Chronic Disease Coalition in supporting this legislation. This is an important step that will lead to better patient outcomes across the state. Thank you for your consideration. Sincerely, Nathaniel Brown
 Director of Advocacy
www.chronicdiseasecoalition.org



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WITNESS NAME			
REGISTERED LOBBYIST:			
WITNESS NAME: RICHARD AUBUCHON		PHONE NUMBER: 573-616-1845	
REPRESENTING: MISSOURI STATE MEDICAL SOCIETY		TITLE: LAWYER - LOBBYIST	
ADDRESS: 112 E. HIGH STREET			
CITY: JEFFERSON CITY		STATE: MO	ZIP: 06510
EMAIL: rich@rmaobby.com	ATTENDANCE: In-Person	SUBMIT DATE: 2/26/2024 1:29 PM	
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WITNESS NAME			
REGISTERED LOBBYIST:			
WITNESS NAME: RYAN DEBOEF		PHONE NUMBER: 573-635-6944	
REPRESENTING: MISSOURI ASSOCIATION OF OSTEOPATHIC PHYSICIANS AND SURGEONS		TITLE:	
ADDRESS: 1423 RANDY LN.			
CITY: JEFFERSON CITY		STATE: MO	ZIP: 65101
EMAIL: ryan@hahndeboef.com	ATTENDANCE: In-Person	SUBMIT DATE: 2/26/2024 10:23 AM	
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MISSOURI HOUSE OF REPRESENTATIVES
WITNESS APPEARANCE FORM

BILL NUMBER: HB 1628		DATE: 2/26/2024	
COMMITTEE: Health and Mental Health Policy			
TESTIFYING: <input checked="" type="checkbox"/> IN SUPPORT OF <input type="checkbox"/> IN OPPOSITION TO <input type="checkbox"/> FOR INFORMATIONAL PURPOSES			
WITNESS NAME			
INDIVIDUAL:			
WITNESS NAME: SARAH JAMISON		PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:		TITLE:	
ADDRESS:			
CITY:		STATE:	ZIP:
EMAIL: sarahpjamison@gmail.com	ATTENDANCE: In-Person	SUBMIT DATE: 2/26/2024 8:21 PM	
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Thank you to Chair Stephens and Vice-Chair Thomas and the entire Health and Mental Health Policy Committee for allowing me to testify. My name is Sarah Jamison, a member of the National Multiple Sclerosis Society. I reside in Bridgeton, Missouri, located in St. Louis County. I was diagnosed with Multiple Sclerosis (MS) on October 16, 2016. Previously, I received co-pay assistance, which was applied to my insurance deductible and out-of-pocket maximum. Now, I still receive copay assistance, but it is not applied to my insurance deductible and out-of-pocket maximum. Because co-pay assistance is not being applied, I am required to pay thousands of dollars, out of pocket, for procedures like MRIs, which means I have to set up payment plans to remain in financial good standing with my health care providers to ensure ongoing treatment. My insurance company and pharmacy benefits manager (PBM) informed me that they accept the co-pay assistance, BUT they will not apply the co-pay assistance to my deductible and out-of-pocket maximum, as intended. My neurologist prescribed for me the specialty medication, Copaxone, in January 2017, and it has worked well in stopping the progression of MS. In 2018, my insurance provider decided not to cover the brand Copaxone and recommended a generic alternative. When I changed to the generic medication, I had two adverse reactions. The second reaction was more severe than the first and resulted in lingering after effects. As a result, my physician submitted an appeal to the insurance company, and I requested approval from my employer. Thankfully, the approvals were granted, and I resumed taking the brand medication Copaxone. I am here to testify, not just for me, but the nearly one (1) million patients living with MS. Managing the symptoms of MS and maintaining a certain standard of living brings its own level of challenges and stress. Add additional financial burden, decisions about which life saving therapies or procedures to move forward with based on cost, takes an emotional and physical toll on the body, which is the enemy of MS. MS medications are very expensive. Mine now cost thousands per month, and it is a relief to know that someone cares and is providing help to cover those costs, but that help isn't being applied as intended. Until real solutions to the challenges of unaffordable MS drugs are found, co-pay assistance from drug manufacturers and other sources must remain available. We need your help to bring an end to Co-pay Accumulator Adjustment Programs to ensure life saving therapies and procedures are accessible to all. Thank you for allowing me this time to share my story. I respectfully ask the Health and Mental Health Policy Committee to vote HB 1628 out of committee. Thank you very much for your time and consideration.



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WITNESS NAME			
BUSINESS/ORGANIZATION:			
WITNESS NAME: SARAH SANCHEZ		PHONE NUMBER: 612-991-7398	
BUSINESS/ORGANIZATION NAME: ALS ASSOCIATION		TITLE: MANAGING DIRECTOR OF ADVOCACY	
ADDRESS: 1950 CRAIG RD, SUITE 200			
CITY: ST. LOUIS		STATE: MO	ZIP: 63146
EMAIL: Sarah.Sanchez@als.org	ATTENDANCE: Written	SUBMIT DATE: 2/26/2024 7:14 AM	

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On behalf of the ALS Association, I am writing in support of the HB 1628, which would create a ban on copay accumulator policies in insurance plans, which would ensure that the value of copay assistance is counted when calculating patient out-of-pocket cost responsibilities. Amyotrophic lateral sclerosis (ALS) is an always fatal progressive neurodegenerative disease that slowly robs a person’s ability to walk, talk, eat, and eventually breathe. The cost of care for someone living with ALS is astronomical, with annual out-of-pocket expenses reaching upwards of \$250,000 per year. As with many people living with complex medical conditions, those with ALS must take various drugs to maintain their health. The copays associated with acquiring them significantly add to this crushing financial burden. One way that people with ALS afford their care is through copay assistance programs, where cards or coupons from nonprofit organizations or drug manufacturers help reduce the cost of drugs. However, insurers and pharmacy benefit managers increasingly use copay accumulator adjustment programs to prevent such assistance from counting towards patient cost-sharing, such as their deductible or annual out-of-pocket maximum. In effect, the insurer is “double dipping” and is paid twice by demanding payment of out-of-pocket costs: first from copay assistance programs provided by drug manufacturers or nonprofits and then again from patients. Copay accumulator adjustment programs do not just harm patients’ finances; they undermine their access to life-saving prescription drugs, making it even more difficult for people living with ALS and other complex medical conditions to adhere to a treatment plan. With lower copays, consumers are more likely to take their medications regularly. We strongly support medical debt reform and the prohibition of copay accumulator adjustment programs. We believe that all Missouri residents should be able to afford necessary treatments by ensuring all payments – made by or on behalf of them – are counted towards their deductible and out-of-pocket maximums. Thank you for your research, time and consideration of this critical legislation.



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WITNESS NAME		
INDIVIDUAL:		
WITNESS NAME: WAYNE LEE		PHONE NUMBER:
BUSINESS/ORGANIZATION NAME:		TITLE:
ADDRESS:		
CITY:		STATE: ZIP:
EMAIL:	ATTENDANCE:	SUBMIT DATE: 2/26/2024 12:00 AM
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WITNESS NAME			
BUSINESS/ORGANIZATION:			
WITNESS NAME: LOUISE PROBST		PHONE NUMBER: 314-721-7800	
BUSINESS/ORGANIZATION NAME: ST. LOUIS AREA BUSINESS HEALTH COALITION		TITLE: EXECUTIVE DIRECTOR	
ADDRESS: 8888 LADUE RD.			
CITY: ST. LOUIS		STATE: MO	ZIP: 63124
EMAIL:	ATTENDANCE:	SUBMIT DATE: 2/26/2024 12:00 AM	
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WITNESS NAME			
REGISTERED LOBBYIST:			
WITNESS NAME: MARK DALTON		PHONE NUMBER: 314-644-4800	
REPRESENTING:		TITLE:	
ADDRESS: 1401 HAMPTON AVENUE			
CITY: ST. LOUIS		STATE: MO	ZIP: 63139
EMAIL:	ATTENDANCE:	SUBMIT DATE: 2/26/2024 12:00 AM	
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WITNESS NAME			
REGISTERED LOBBYIST:			
WITNESS NAME: MICHAEL J. HENDERSON		PHONE NUMBER: 573-893-4241	
REPRESENTING: MISSOURI INSURANCE COALITION		TITLE: GENERAL COUNSEL & GOVERNMENT AFFAIRS DIRECTOR	
ADDRESS: 220 EAST HIGH STREET, SUITE B			
CITY: JEFFERSON CITY		STATE: MO	ZIP: 65101
EMAIL: mike@moinsurancecoalition.com	ATTENDANCE: In-Person	SUBMIT DATE: 2/26/2024 10:43 AM	
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WITNESS NAME			
REGISTERED LOBBYIST:			
WITNESS NAME: SHANNON COOPER		PHONE NUMBER: 660-890-1432	
REPRESENTING: AMERICA's HEALTH INSURANCE PLANS, BLUE CROSS BLUE SHIELD OF KC		TITLE:	
ADDRESS: 208 MADISON			
CITY: JEFFERSON CITY		STATE: MO	ZIP: 65101
EMAIL:	ATTENDANCE:	SUBMIT DATE: 2/26/2024 12:00 AM	
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WITNESS NAME		
BUSINESS/ORGANIZATION:		
WITNESS NAME: LEIGH ANNE HAUN		PHONE NUMBER:
BUSINESS/ORGANIZATION NAME: MISSOURI DEVELOPMENTAL DISABILITIES COUNCIL		TITLE: POLICY COORDINATOR
ADDRESS: PO BOX 687, 1706 E. ELM STREET		
CITY: JEFFERSON CITY		STATE: MO
		ZIP: 65102
EMAIL:	ATTENDANCE:	SUBMIT DATE: 2/26/2024 12:00 AM
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