



May 1, 2024

The Honorable Xavier Becerra
Secretary
U.S. Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Re: Urging HHS to enforce the *CY20 Notice of Benefit and Payment Parameters* following U.S. District Court Ruling

Dear Secretary Becerra:

We are writing to you as a coalition of 80+ organizations representing vulnerable people across the country living with serious and complex chronic illnesses. People living with chronic conditions often face significant challenges getting the health care they need even when they have health insurance, because of increasing deductibles and cost-sharing that must be paid to gain access to prescription drugs.

These copay accumulator adjustment policies, used by health insurers and pharmacy benefit managers (PBMs), are not just policies on paper. They have real-life implications for people living with serious chronic illnesses who rely on copay assistance from charitable foundations or prescription drug manufacturers. These policies, by keeping these payments without crediting them to the patient on whose behalf they were paid, are undermining the very cost-sharing protections included in the Affordable Care Act.

We deeply appreciate the efforts of the Biden Administration and the Department of Health and Human Services in addressing the cost of prescription drugs for people living with chronic illnesses. The out-of-pocket cap on cost-sharing for Medicare enrollees is a significant step that will transform the lives of millions. We now look to your agency to extend similar protection to patients living with chronic illness who have commercial health insurance by enforcing the provision of the 2020 Notice of Benefit and Payment Parameters (NBPP) that restricts the use of copay accumulator adjustment policies, as per the 2023 decision by the U.S. District Court in DC.

HHS has said that it will not enforce this rule and will instead issue new regulations defining cost-sharing in commercial health insurance. People living with serious, life-threatening conditions should not be made to wait for a new regulation when an existing regulation would offer them protection from abusive insurers and PBM practices if it were enforced by the regulatory agency in charge. **We urge you to immediately issue guidance to health insurers and PBMs that they must immediately comply with the 2020 NBPP provision restricting the use of copay accumulator adjustment policies.**

We understand that your agency may also undertake a new regulatory process to further define cost-sharing in the future. When that rule is drafted, we urge you to ensure that it serves, first and foremost, the goal of ensuring that necessary medical care is affordable for people with health insurance.

In a recent congressional hearing, you were asked about enforcing this rule by Representative Buddy Carter (R-GA). As part of your response, you asked for examples of patients who were denied access to their medications due to copay assistance accumulator policies. As advocates for vulnerable populations grappling with various illnesses and diseases across the nation, we hear frequently from patients about the widespread negative impact of these programs. Here are just a few examples of individuals whose lives have been impacted:

Anonymous (Wisconsin) – An arthritis patient with a Marketplace plan in WI who recently contacted the Arthritis Foundation is confused about why her copay assistance is not counting towards her deductible in the wake of the court ruling. Due to her health plan’s non-compliance, she cannot afford the \$2,300 out-of-pocket expense for her drug and cannot fill her prescription. This could lead to significant and irreversible health consequences and is one of certainly many examples of the harmful impacts of these policies.

Robin Lancaster (Kentucky) – Robin, diagnosed with primary myelofibrosis, relied on copay assistance to afford her medication. However, her insurer abruptly implemented a copay accumulator ban in 2019, leaving her with thousands of dollars in additional costs that she could not afford.¹

Alyssa Dykstra (California): *Alyssa has battled autoimmune arthritis since she was 2 years old.* old, found herself facing an unexpected medical bill for \$1,000. It took hours on the phone with customer service to discover the addition of a copay accumulator clause that caused the problem.²

Darla Bell (Texas)—*In 2022, Darla, who manages a chronic medical condition, paid \$800/month for a bronze plan with a \$9,100 deductible.* She depends on copay assistance to afford her medication. Without warning, her insurer adopted a copay accumulator policy, suddenly burdening Darla with full deductible payments while pocketing the assistance meant to support her.³

We have included in the appendix more than 40 additional examples of patients who have shared their stories publicly. These policies are widespread, impacting patients with common marketplace and workplace insurance plans.

You have an opportunity to enforce the 2020 Notice of Benefits and Payments Parameters to alleviate patients' financial strain and mitigate the detrimental effects of copay accumulator programs. These schemes undermine copay assistance by preventing assistance funds from offsetting out-of-pocket costs. This results in an increased financial burden for patients, forcing many to forego necessary medications *despite having insurance*.

We would be happy to meet with you so you could hear directly from patients impacted by copay accumulator adjustment programs.

The repercussions of failing to address this issue are significant. Access to essential medication is vital for both managing chronic conditions and avoiding costly complications that burden both the patient and the healthcare system at large. Secretary Becerra, your commitment to enforcing the 2020 Notice of Benefits and Parameters would mark a significant step towards protecting patients nationwide. As a coalition, we urge you to recognize the immense impact this issue has on individuals across the country, and to address it without delay.

These are catastrophic outcomes for patients who, without assistance, are desperate and feel helpless. For this reason, we urge HHS to comply with the district court’s ruling and reinstate the CY20 NBPP, which bans the use of **copay accumulator adjustment programs except when a generic alternative is available**.

Below are more examples and statistics to highlight the severity of the issue facing patients today.

Prevalence of Copay Accumulator Adjustment Programs in Private Plans

Unchecked: Copay Accumulator Adjustment Policies in 2024—This report, released by The AIDS Institute in February 2024, found that two-thirds of all individual marketplace plans have copay accumulator adjustment policies. 11 states have 75%—100% of their plans carrying a copay accumulator adjustment program.

¹ [Robin Lancaster: an unexpected bill at the pharmacy - PAN Foundation](#)

² [Chronically ill patients facing a lack of insurance coverage - by law - Capitol Weekly](#)

³ [Copay Accumulator Adjustment Programs: Anti-Patient Practice - Patients Rising Stories](#)

All Copays Count Patient Story Hub—The All Copays Count Coalition has served as a hub to collect stories from patients being subjected to copay accumulator adjustment programs. These patients represent a very broad range of diseases and conditions, including multiple sclerosis, hemophilia, cystic fibrosis, psoriasis, arthritis, and many more.

Accumulator Practices Harm Patients - Coad Family Story - Copay Accumulator Adjustment Programs blindsided patients and families at the pharmacy counter with thousands of dollars of out-of-pocket expenses. That is exactly what happened to the Coad family, who were hit with a \$2,000 price tag when picking up a prescription for their daughter, who had been diagnosed with Juvenile Arthritis.

Op-Ed: Lawmakers Should Do This to Help Families Dealing with Cystic Fibrosis - In this op-ed, the mother of a cystic fibrosis patient details the struggles her family was subjected to and the medical debt forced upon them, because her insurer instituted a copay accumulator adjustment program, meaning they were responsible for thousands of dollars out-of-pocket.

—My Copay Assistance No Longer Counts—Yours May Be Next—In another example of being subjected to thousands of dollars in expected out-of-pocket expenses, Tami Seretti details her journey to find a treatment that works for her psoriasis. Tami's copay for her medication was manageable until her insurer instituted a copay accumulator adjustment program, forcing her to pay \$1,250 per month to stay stable on her treatment.

For the patients represented in the stories above and numerous other patients who are forced to decide between their medications and other life necessities such as rent/mortgage, food, and transportation, **we urge HHS to abide by the D.C. District Court ruling and reinstate the CY20 NBPP, effectively banning the usage of copay accumulators.**

Sincerely,

All Copays Count Steering Committee:

The AIDS Institute

Arthritis Foundation

Cancer Support Community

Immune Deficiency Foundation

National Bleeding Disorders Foundation

National Multiple Sclerosis Society

Cc: Ellen Montz, *Deputy Administrator and Director, CCIO*

Jeff Wu, *Deputy Director, Policy, CCIO*

Appendix

1. *Annabelle Gurwitch (California)* – Annabelle, tackling cancer, found herself in a confusing web of insurance schemes. After changing coverage, she was blindsided by unexpected charges for her treatment and struggled to get a clear explanation from her insurer. Source: [The Washington Post, September 2022 - Tackling cancer while battling the insurance system](#)
2. *Alyssa Dykstra (California)* – Alyssa was diagnosed with auto-immune arthritis at the age of two. She relied on copay assistance to offset the initial expense of a high deductible on her PPO insurance plan. Source: [Capitol Weekly, December 2022 - Chronically ill patients facing a lack of insurance coverage — by law](#)
3. *Mary Hawley (California)* – Mary uses an expensive drug for rheumatoid arthritis and has long benefited from manufacturer coupons, which helped her meet her insurance deductible until her insurer implemented a copay accumulator policy. This policy prevents counting those coupons towards her deductible, significantly increasing her out-of-pocket costs. Source: [Los Angeles Times, 2023 - They're called 'co-pay accumulators,' and they're a way insurers make you pay more for meds](#)
4. *Brian Callanan (Florida)* – Brian lived with cystic fibrosis and relied on co-pay cards to help cover expenses on high-cost drugs to manage this disease. Brian's insurer changed its policy and stopped counting those payments toward his annual deductible. Source: [Institute for Patient Access, January 2019 - My Co-Pay Accumulator Story](#)
5. *Lauren Killgore (Florida)* – Lauren discovered in 2017 that her husband's \$12,000 copay card for his hemophilia medication no longer counted towards their \$6,500 deductible due to a new copay accumulator policy by their insurance, forcing them to pay the full deductible upfront during a critical health crisis. Source: [WUSF Public Media, June 2019 - Insurance Companies Adopting Policies That Make Medications Unaffordable for Patients](#)
6. *Anonymous (Florida)* – After years of treatment challenges, the patient found effective medication but faced harsh insurance policies. Despite high out-of-pocket and premium costs, copay accumulators prevent copay assistance from reducing these financial burdens. Source: [Hemophilia Foundation of Greater Florida, April 2020 - A Copay Accumulator Story](#)
7. *Nicole Hill (Florida)* – Nicole's daughter's essential antiseizure medication costs \$1,500 monthly, but even with a \$1,000 manufacturer's coupon, a copay accumulator plan only credits them \$500 towards their deductible, despite the insurer receiving the full payment. Source: [Tallahassee Democrat, February 2023 - Florida legislators must ensure patient Rx affordability](#)
8. *Robin Lancaster (Kentucky)* – Robin, diagnosed with primary myelofibrosis, relied on copay assistance to afford her medication. However, her insurer abruptly implemented a copay accumulator ban, costing her thousands of dollars. Source: [PAN Foundation - Robin Lancaster: an unexpected bill at the pharmacy](#)
9. *Kristine Binette (Maine)* – Kristine navigates the complexities of health insurance with a prescription savings card that lowers the monthly cost of Delia's \$800 medication to \$50. However, due to copay accumulator programs, the full payment does not count towards the deductible, leaving the full deductible still to be met each month. Source: [Portland Press Herald, April 2022 - Maine Voices: Unfair copay tactic allows health insurers to double-dip](#)
10. *Nora Ancel (Missouri)* – Nora and her two children, all afflicted by a rare bleeding disorder, face medicine costs of over \$10,000 each per year. After years of benefiting from assistance programs, a policy change by their insurer blocked these aids from reducing their expenses, severely impacting their family budget. Source: [Springfield News-Leader, February 2023 - MO lawmakers take aim at insurance policies that penalize patients who use drug coupons](#)
11. *Beth Waldron (North Carolina)* – Beth relied on blood thinner medication when her insurance provider stopped covering this medication. She depends on the assistance program to afford the medication, while her insurance plan excludes any assistance dollars from counting toward the out-of-pocket total and deductible. Source: [USA Today, November 2022 - Is prescription copay assistance contributing to rising drug prices? Why buyers should beware.](#)
12. *Kristen Catton (Ohio)* – Kristen has multiple sclerosis, which she's long managed with medications paid for by copay assistance. In May 2018, her insurer adopted a copay accumulator, as a result, she's had to consider rationing her medication. Source: [Tulsa World, January 2023 - Health insurance cost-shifting is driving patients' financial burden higher;](#) [NPR, May 2018 - Why Some Patients Getting Drugmakers' Help Are Paying More](#)
13. *Randi Clites (Ohio)* – Randi's son Colton suffers from severe hemophilia, which costs over \$400,000 annually. The family relies on copay assistance from various sources to afford vital medications. Despite high insurance costs exceeding thousands of dollars a month, recent clampdowns by insurers on copay

assistance have exacerbated their financial challenges. Source: [ABC 6 WSYX Columbus, November 2022 - Will your insurance company cover the copay for a costly drug?](#)

14. Ashley Krivohlavek (Oklahoma) – Ashley was diagnosed with psoriatic arthritis and needs costly prescription drugs to manage this painful condition. In recent years, she took advantage of co-pay assistance programs that provided coupons to cover some of the cost of care until her insurance company was no longer counting the contribution of co-pay cards toward her deductible. Source: [The Oklahoman, March 2021 - Make co-pay assistance count toward deductible, out-of-pocket expenses](#)
15. Elizabeth Stafford (Oregon) – Elizabeth’s son relies on expensive medication that manages his Psoriatic Arthritis. When her husband lost a job, the family had to change their insurance plan, which did not put copay assistance towards their out-of-pocket maximum, leaving the family with thousands of dollars in additional costs. Source: [Oregon Legislature Patient Story Submission](#)
16. Madonna Maguire Smith (Oregon) – Madonna’s family each battles chronic bleeding disorders and initially struggled to meet their annual out-of-pocket maximum until they received copay assistance. However, their financial relief was complicated by insurer-implemented copay accumulator policies, which prevent these coupons from counting towards their out-of-pocket limits. Source: [Statesman Journal, February 2023 - Patients 'stuck in the middle' of battle over medication costs could get legislative help](#)
17. Tami Seretti (Pennsylvania) – Tami faces a steep increase in her psoriasis treatment copay, rising from \$35 to \$1,250 monthly. On a disability payment of \$1,276 a month, she is left with only \$26 after the copay, unable to afford other necessities or medicines without copay assistance. Source: [TribLIVE, February 2022 - Tami Seretti: My copay assistance no longer counts — yours may be next](#)
18. Paul Adam (Rhode Island) – Paul, diagnosed with psoriatic arthritis, relied on a third-party copay assistance program that covers his \$2,400 monthly copay in full. In April 2023, without notice, his insurance company stopped applying copay assistance to his deductible. Source: [The Providence Journal, April 2023 - RI must join other states that have laws prohibiting copay accumulator programs](#)
19. Kate Tokarski (Rhode Island) – Kate’s experience with the co-pay accumulator program has notably increased the family’s financial burden, as it unexpectedly excluded third-party payments from counting towards the deductible, intensifying the challenge of affording necessary treatments for their three children with multiple conditions. Source: [Boston Globe, May 2023 - R.I. Assembly should pass bills to count co-pay assistance toward a patient’s insurance deductible](#)
20. Darla Bell (Texas) – Darla, managing a chronic medical condition, depended on copay assistance to access her medication. Without warning, her insurer adopted a copay accumulator policy, suddenly burdening Darla with full deductible payments while pocketing the assistance meant to support her. Source: [Patients Rising - Copay Accumulator Adjustment Programs: Anti-Patient Practice](#)
21. Amanda Wolgamott (Texas) – Amanda’s son has a rare condition — Hemophilia A. Their family relied on a copay card that helped contribute to the cost of the boy’s medicine until their insurer implemented a “copay accumulator,” which kept taking their copay assistance while also asking the family to pay the full deductible. Source: [Houston Chronicle, April 2021 - Curb copay accumulators so kids like my son can focus on growing up](#)
22. Jordan Green (Texas) – Jordan has multiple sclerosis and relies on copay assistance. At the beginning of the year, his insurance had adopted a copay accumulator adjustment program, leaving him responsible for the full deductible. Source: [Medium - Copay Accumulator Programs Are the Next Major Threat to Patients, June 2019](#)
23. Ashley Bowen (Utah) – Ashley has a 6-year-old son with a blood condition called Hemophilia. In 2019, her insurance company suddenly implemented the copay accumulator adjustment, putting them in debt to pay for her son Carter’s Hemophilia medication, which helps stop uncontrollable bleeding. Source: [Fox 13 Salt Lake City, January 2023 - Parents hope the legislation will help save on prescription drug costs;](#)
24. Dan Brickey (Utah) – The cystic fibrosis medication for Dan’s daughter Ali was set to increase from \$180 to \$43,600 annually out of pocket in 2023. The family greatly relied on copay assistance programs but had to opt for a new insurance plan that would not have a copay accumulator adjustment program. Source: [STAT News, February 2023 - 'Caught in the middle: A battle between Vertex and insurers is leaving cystic fibrosis patients with crushing drug costs](#)
25. Steven Sivak (Utah) – Steven, diagnosed with cancer, faces billing challenges when his insurer’s copay accumulator policy fails to credit his copay assistance, worsening his financial burden as he struggles with a \$200,000 annual medication cost. Source: [Fox 13 Salt Lake City, February 2023 - Park City man needs answers after cancer medication canceled](#)
26. Jen Hepworth (Utah) – Jen’s daughter was diagnosed with cystic fibrosis and relies on medication to keep her out of the hospital. The drug costs \$311,000 per year, but copay assistance programs help cover the cost. However, their insurance company adopted a copay accumulator adjustment program that does not

- allow the assisted funds to count toward her deductible. *Source: [Fox 13 Salt Lake City, January 2023 - Parents hope the legislation will help save on prescription drug costs](#); [Deseret News, January 2022 - Lawmakers should do this to help families dealing with cystic fibrosis](#).*
27. *Jami Carter (Utah)* – Jami relies on copay assistance to afford his medication for multiple sclerosis. After his insurance adopted a copay accumulator program, Jami had to choose between risking permanent brain damage or continuing to pay thousands of dollars. *Source: [Utah Policy, February 2023 - End predatory copay accumulator programs to help people like me](#)*
 28. *Jason (Utah)* – Having recently transitioned off state assistance and started a well-paying job, Jason was ineligible for further state help but couldn't afford his co-pay. As a result, he went without his HIV medications for six weeks and expected another eight-week gap, increasing his health risks and stress about future access to necessary treatment. *Source: [Utah Aids Foundation - Patient Story](#)*
 29. *Kaela Rawlins (Utah)* – Kaela's family consistently faces financial stress due to the lack of generic medication options and the high costs of her children's medication. For the health of her children, the family pays thousands of dollars to afford the medication for them since their insurer adopted a copay accumulator program. *Source: [Utah All Copays Count Coalition - Parents of Children with Cystic Fibrosis](#)*
 30. *Melissa El Menaouar (Wisconsin)* – Melissa relied on copay assistance to afford her medication for Primary Biliary Cholangitis. However, this vital support was increasingly undermined by "copay accumulator programs," which exclude such assistance from counting towards deductibles, leaving her to face sudden, steep out-of-pocket costs. *Source: [The Cap Times, February 2022 - Loss of copay assistance would impoverish patients](#)*
 31. *Jim Turk (Wisconsin)* – Jim relied on copay assistance to manage his condition. However, with the rise of the copay accumulator program, this assistance no longer counts towards deductibles, forcing Jim to choose between financial stability and essential treatment. *Source: [Milwaukee Journal Sentinel, October 2021 - Why Wisconsin lawmakers need to protect the value of copay assistance](#).*
 32. *Denise Seyfer (Wisconsin)* – Denise relied on copay coupon cards and discounts to afford medically necessary medications, but her insurance plan implemented a copay accumulator program in place, forcing her to pay full price for her medications, which she could not afford. As a result, Denise almost lost access to the life-saving medication. *Source: [The Cap Times, May 2021 - Denise Seyfer: I almost lost access to lifesaving medication — Senate Bill 215 would ensure that I don't](#)*
 33. *Anndi McAfee* – Anndi suffers from a rare disease and requires treatment with an orphan drug. At the time, this drug was the third most expensive on the planet. She has been on a copay assistance program ever since she began treatment, but in September 2020, her insurer adopted a copay maximizer program. *Source: [Drug Channels, November 2020 - SaveonSP's Copay Maximizer Failed Me: A Patient's Perspective](#)*
 34. *Jack Haskins* – Jack was forced to pay \$4,500 out of pocket for insulin and biologics due to copay accumulators. *Source: [Patients Rising Twitter - Jack Haskins shares his story](#)*
 35. *Lillian Karabaic* – the cost of Lillian's medication for her rheumatoid arthritis has spiked to twelve thousand dollars a month – 15 times more expensive than it was seven years ago. Additionally, her insurance adopted a copay accumulator program, leaving Lillian with a bill for thousands of dollars monthly. *Source: [An Arm and a Leg Show, March 2022 - Swimming with Sharks](#)*
 36. *Kip Burgess* – Kip initially benefited from an assistance program to cover expenses. When the financial assistance didn't apply toward his deductible, Burgess had to exhaust his savings to meet thousands of dollars in medical costs. *Source: [KFF Health News, December 2018—For The Asking, a check is in the mail to help pay for costly drugs](#).*
 37. *Dr. Samy Metyas* – Dr. Metyas sees patients with various chronic conditions such as arthritis, lupus, HIV, cancer, autoimmune diseases, multiple sclerosis and hemophilia. Dr. Metyas details the experiences of patients that have been subjected to copay accumulators. *Source: <https://capitolweekly.net/california-legislators-must-prioritize-patients-over-profits/>*
 38. *Victoria Killian (California)* – Victoria discovered in 2022 that her insurer would not count copay assistance toward her annual deductible, which could potentially lead to struggles affording medication. *Source - <https://www.dailynews.com/2024/04/25/paying-for-my-meds-twice-california-law-needed-to-protect-patients/>*
 39. *Krin (Wisconsin)* – After retiring, Krin was diagnosed with stage 3 uterine cancer. They've relied on copay assistance to afford the \$2,500 a month treatment. However, their plan has a copay accumulator adjustment program, forcing Krin to take the money out of her retirement plan in order to afford the treatment. *Source - <https://www.fightcancer.org/krin-gary-westby-wi>*

40. *Julie (Ohio)* – Julie is a childhood cancer survivor who, 47 years later, still must take treatments to address the side-effects from the medications that treated her cancer. These medications are expensive, and her insurance has a copay accumulator adjustment program. *Source* - <https://www.fightcancer.org/julie-vandalia-oh>
41. *Jay* – Jay was 10 years old when he was diagnosed with Crohn’s disease. His biologic treatment allows him to manage his condition. However, he was forced to pay a \$7,000 bill when he discovered that his plan had a copay accumulator adjustment program. This forced him to use his family’s emergency fund to pay for his treatment. *Source* - <https://www.crohnscolitisfoundation.org/jays-story>
42. *Megan R. (Texas)* – After being diagnosed with Common Variable Immune Deficiency, she was forced to spend hours of time on the phone with her insurer and thousands of dollars out-of-pocket to afford her treatment. *Source* - <https://infusionaccessfoundation.org/patient-stories/the-resilient-road>
43. *Larry Bahr (California)* – Larry relied upon copay assistance for over a decade to afford his biologic treatment which cleared his skin of nearly all psoriasis plaques and worked “like night and day” compared to other treatments. In 2019, Larry’s insurance implemented a copay accumulator and he got hit with a \$1600 bill that January, plus \$600 monthly payments thereafter. “That’s a big financial shock,” says Larry. *Source*: [National Psoriasis Foundation, 2024 – Speaking Out is Empowering](#)
44. *Marguerite Casillas (California)* - In 2022, Marguerite had to change her insurance provider and was required to pay a large deductible. Fortunately, there was patient assistance available to help her afford her medication. However, her insurance company did not count her patient assistance funds toward her deductible, leaving her on the hook for the full cost of the medication. *Source* – <https://www.sfchronicle.com/opinion/openforum/article/ms-copay-accumulator-19423538.php>
45. *Anonymous* – This patient utilizes patient assistance to cover her annual deductible and copays. However, since the insurance company used the entirety of her copay assistance and did not count it toward her deductible, there was no assistance left over to help cover her copay for the rest of the year.