PIPELINE TO PROFITS: HOW DRUG MIDDLEMEN MAKE THEIR MONEY

The path of prescription drugs from the factory to the patient is complicated. Here, Julie Appleby of Kaiser Health News explains how money flows through the system and contributes to the cost of a 30-day supply of a hypothetical brand-name medicine.

KEY PRICES IN THE PROCESS

After a drugmaker develops a brand-name product and wins marketing approval, there are two key prices that it needs to begin selling:

LIST PRICE (WAC)

Set by drugmakers, this **wholesale acquisition cost** or **WAC** covers research, production and profits

WHOLESALE PRICE (AWP)

Called **average wholesale price** or **AWP**. It's the WAC multiplied by a set percentage.

Generally known as "ain't what's paid" — as you'll see in the chart below

$250 +20%= $300

THE PATIENT

Those with insurance pay an amount set by their benefit plan. Two common methods:

$25 CO-PAYMENT

INSURED

- A percentage of the cost of the drug.
- Flat-dollar co-payments, say **$10 to $50** per prescription.

$300 ◂ NET PAID OUT [1]

UNINSURED

Depending on the pharmacy, some might pay less, while others pay more.

1 — The price may be lowered by manufacturer or pharmacy discount programs.

INSURER OR EMPLOYER

Employers/insurers sign contracts with pharmacy benefit managers that include specific formulas for how much they reimburse PBMs for the cost of each prescription, generally an amount 15% to 22% below AWP. They sometimes also get rebates from drugmakers that are funneled through the PBM.

$232 ◂ REIMBURSEMENT TO PBM
- $50 ◂ REBATE FROM DRUGMAKER
$182 ◂ PAID BY INSURER/ EMPLOYER FOR THE DRUG

PHARMACY BENEFIT MANAGER (PBM)

A firm hired by insurers or employers to manage claims, set up networks of pharmacies, create drug formularies and negotiate discounts and rebates with drug makers.

PBMS are reimbursed by insurer/employers amounts that are generally above what the PBMs have paid pharmacies. They can also collect rebates from manufacturers.

$229 ◂ PAID TO PHARMACY
$232 ◂ REIMBURSEMENT FROM INSURER OR EMPLOYER
$3
+ $12.50 ◂ REBATE FROM DRUGMAKERS
$15.50 ◂ NET RECEIVED BY PBM

PBM payments to the pharmacy are based on a percentage of the AWP, which is higher than the list price, even though no one has actually paid that amount.

THE PHARMACY

The contract between the pharmacy and wholesaler for brand-name drugs generally sets a price below the WAC.

Note: Different payment arrangements are set for generics.

$250 ◂ WAC
- 4%
$240 ◂ PAYMENT TO WHOLESALER
+$229 ◂ REIMBURSEMENT FROM PBM
+$25 ◂ PATIENT CO-PAY
$14 ◂ NET RECEIVED BY PHARMACY

THE WHOLESALER

The contract between the drugmaker and the wholesaler discounts the WAC price by 2% to 5%.

$250 ◂ WAC
- 5%
$237.50 ◂ PAID TO DRUGMAKER
+$240 ◂ PRICE PAID BY PHARMACY
$2.50 ◂ NET RECEIVED BY WHOLESALER

REBATE TO INSURER AND BENEFIT MANAGER

$50 + $12.50 = **$62.50**

The PBM has negotiated a rebate on this particular drug. Drugmakers sometimes offer rebates in order to win favorable spots on an insurer's or PBM's formulary, so more patients take their drugs.

Rebates range widely, but can be **25%** or more of the drug's WAC. In this case, let's assume the PBM gets back **25%**, or **$62.50**.

THE DRUGMAKER

$237.50 ◂ FROM WHOLESALER
-$62.50 ◂ REBATE TO INSURERS AND PBMS
$175 ◂ NET RECEIVED BY DRUGMAKER

THE REBATES

NCPA
NATIONAL COMMUNITY PHARMACISTS ASSOCIATION

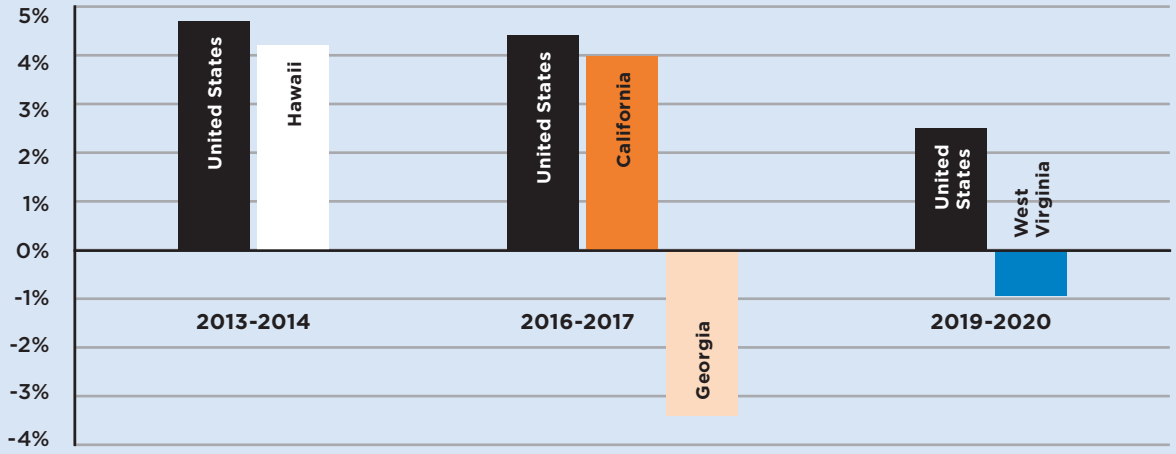
PBM REFORM HAS NOT RAISED COSTS FOR PATIENTS AND PAYERS

State legislative efforts protecting patients from pharmacy benefit managers' (PBMs') conflicts of interest **do not raise health insurance premiums**. PBMs claim that legislation protecting patients, payers, and pharmacies from their opaque business practices raise health insurance costs. But the facts tell another story!

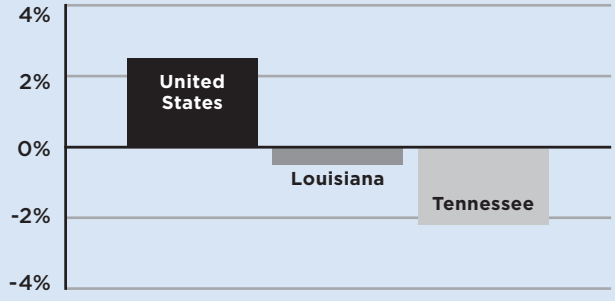
When states pass meaningful PBM reform, the increase in their average health insurance premium costs have been lower than the nationwide average. In fact, some states have actually seen a decrease in their premium costs!

Compare the change in premiums when states passed PBM reform legislation to the national average.[1]

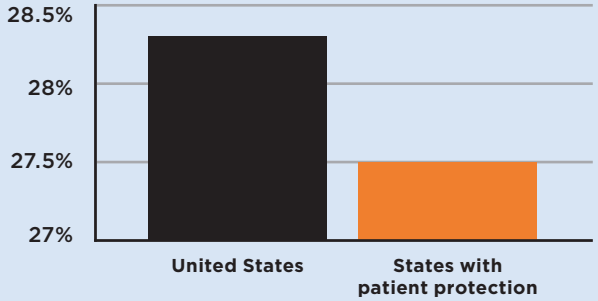
States that protect patients from mandated use of a mail-order pharmacy



States that prohibit PBMs from reimbursing PBM-owned pharmacies at higher rates than non-affiliated pharmacies (2019-2020)



States that protect patients from PBM penalties (e.g., higher copays) for utilizing the in-network pharmacy of their choice (2013-2020)[2]



PBMs have enormous control over patients' prescription drug benefits. They design formularies and provider networks, giving them outsized influence over the medications and the pharmacies a patient can utilize. PBMs and their conflicts of interest are responsible for rising prescription drug benefit costs. Limiting those conflicts of interest helps patients by empowering them to make healthcare decisions for themselves, decreasing their out-of-pocket costs, and protecting access to community pharmacy services; all without raising their health insurance premiums.

1. Numbers based on data from the Kaiser Family Foundation (www.kff.org).

2. States include Delaware, Mississippi, North Carolina, and South Dakota.

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Independent Neighborhood Pharmacies:

Accessible and affordable care; trusted and valued health care providers

Founded in 1898, the National Community Pharmacists Association is the voice for the community pharmacist, representing nearly 19,400 pharmacies that employ over 215,000 individuals nationwide. Community pharmacies are rooted in the communities where they are located and are among America's most accessible health care providers. To learn more, visit www.ncpa.org.

Kentucky

Number of independent community pharmacies:	**477**
Total sales:	**$1,650,331,278**
Pharmacy sales:	**$1,534,808,089**
Front-end sales:	**$115,523,189**
Total number of employees:	**5,295**
Total prescriptions filled:	**27,512,406**
Part D prescriptions filled:	**9,904,466**
Medicaid prescriptions filled:	**5,227,357**
Additional economic activity* generated by independent community pharmacy:	
Sales:	**$1,485,298,150**
Employment:	**2,118**

Financial data represented here is for the 2020 tax year.
For more information, please contact the NCPA Advocacy Center at mrule@ncpa.org.

*Additional economic activity refers to the increase in economic activity – usually at the local level – that results as pharmacy employees spend and invest their earnings. The effect of that spending is compounded as workers spend their money at local businesses. Those businesses in turn have additional income to invest locally. As each round of spending weaves through the economy, community pharmacy's impact is multiplied.

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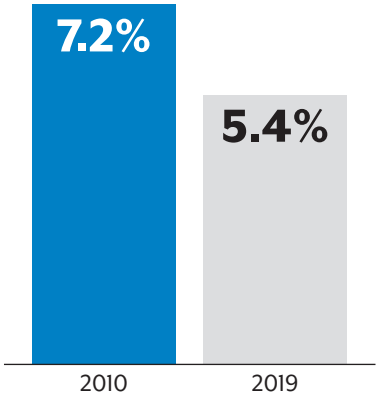
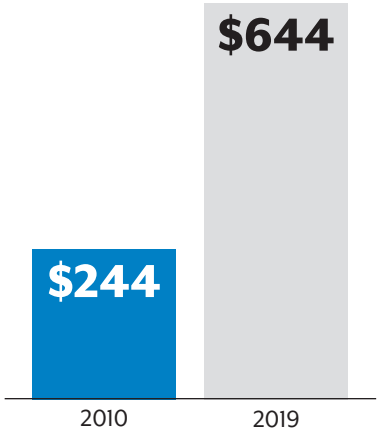
The *Costs* of Mail Order Rx

Consumers, employers, and public health officials should consider the potential risks before they allow health insurance companies to steer patients into mail order.

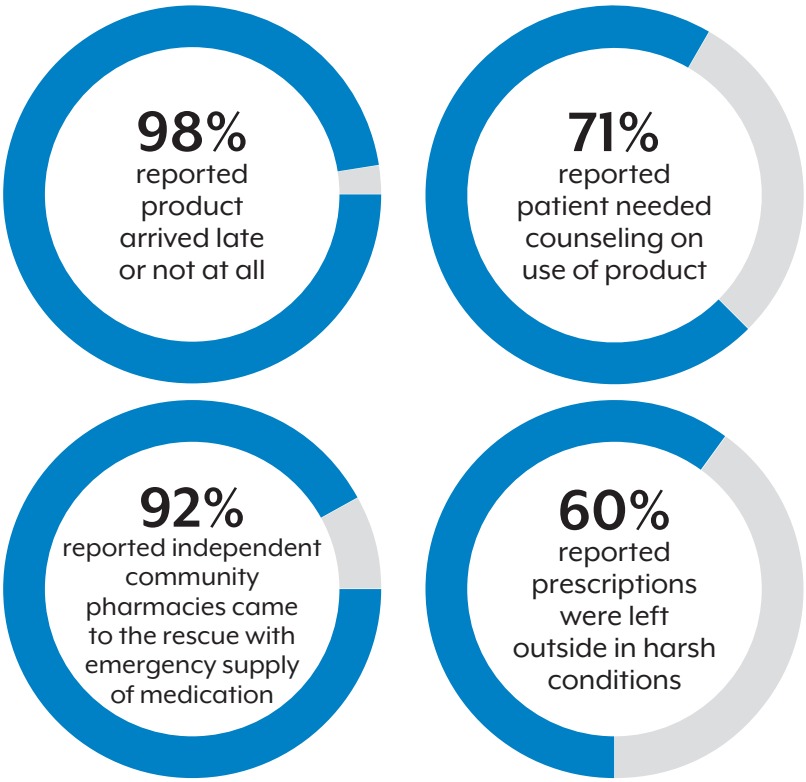


[1]THE PERCENTAGE OF CONSUMERS CHOOSING MAIL ORDER Rx HAS DECREASED OVER TIME



[1]THE AVERAGE MAIL ORDER Rx COST HAS GROWN 164%

PHARMACISTS REPORT PATIENT ISSUES WITH MAIL ORDER[2]



[3]**Between 59°-77°F** is the temperature recommended to store most medications, but mailbox **temperatures may exceed 150°F in summer**!

WASTE NOT WANT NOT[4]

$3,166.87 in mail order waste. "A customer brought in a sack full ... her husband had passed away, and wanted us to donate the medications for someone else to use. Unfortunately we couldn't."

One patient had **six months over-supply** due to 90-day filling and therapy changes that cost **approximately $4,000.**

Tricare[5]

THREE STRIKES AND YOU'RE OUT!

Active military and veterans who choose a local pharmacy instead of mail order three times are then responsible to pay 100% of the cost for many commonly used drugs!

Our military men and women and military veterans help keep our country free. **Yet their own freedom to choose their own pharmacy is limited when it comes to their prescription drug benefit.**

1. ncpa.org/iqviadata | 2. ncpa.org/2020mailsurvey | 3. baystatehealth.org | 4. ncpa.org/pbm-resources | 5. tricare.mil/homedelivery

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To Reduce Prescription Prices, Hold Middlemen Accountable

By **George Huntley** (June 23, 2021, 3:02 PM EDT)

George Huntley

President Joe Biden froze all the rules and regulations issued in the Trump administration's final days. Such pauses are fairly common; new presidents typically want to review, and sometimes shelve, their predecessors' last-minute gambits.

But unfortunately, Biden's freeze has delayed a prescription drug reform that could save Medicare beneficiaries billions at the pharmacy counter.[1] Quickly implementing that rule — which targets middlemen in the drug supply chain — would help safeguard seniors' health.

Tens of millions of Americans struggle at the pharmacy. The Kaiser Family Foundation found that 30% of patients don't take their prescriptions as prescribed due to cost — choosing instead to cut pills, skip doses or not fill prescriptions at all.[2]

COVID-19 has only exacerbated this problem. The pandemic has devastated wide swaths of the economy, leading to mass layoffs and pay cuts for many Americans battling expensive chronic conditions like diabetes.[3]

Diabetes has proven one of the greatest risk factors for COVID-19 deaths.[4] A recent study found that 40% of people who died from COVID-19 lived with the condition — even though just 10.5% of the population has diabetes.[5]

The Centers for Disease Control and Prevention stresses the importance for people with diabetes to "continue taking ... diabetes pills and insulin as usual," to reduce the potential for severe complications from COVID-19.[6]

Unfortunately, the average list price of diabetes medications and supplies jumped 58% from 2014 to 2019.[7] List prices for insulin in particular, a vital medicine for more than 8 million[8] Americans with diabetes, have tripled over the past decade.[9]

While list prices have been rising,[10] manufacturer net revenues for insulin have declined[11] and net revenues from brand-name drugs have remained nearly flat.[12]

Middlemen known as pharmacy benefit managers, or PBMs, contribute to rising list prices. Insurance companies — including the insurers that sponsor Medicare prescription drug plans — hire these PBMs to negotiate with drug companies and determine which treatments to cover.

Drugmakers offer significant rebates to PBMs to incentivize them to cover their medicines — and thus make them available to more potential patients. It's just like when cereal or toilet paper manufacturers offer discounts to retailers to ensure their products are stocked on the most accessible, eye-level shelves. In 2018, pharmaceutical companies offered $166 billion in rebates, up 63% from the $102 billion they offered in 2014.[13]

Essentially, middlemen are demanding bigger and bigger rebates and companies are granting those demands in return for access. In the case of insulin, rebates often exceed 70%. So if a vial of insulin has a list price of $300, the PBM will typically obtain it for just $90.

There's a catch, though. These negotiated rebates are secret. When patients go to the pharmacy to fill their prescriptions, their copays and co-insurance payments are calculated based on the list price — not the price the PBM paid.

If an insurance plan requires a 20% co-insurance payment, a patient would pay $60 to fill his or her prescription — one-fifth of the $300 list price. But if the discounts were shared at the pharmacy, the patient would instead owe $18 — one-fifth of the $90 discounted price.

Forcing middlemen to pass along these savings through lower copays could save Americans with diabetes up to $900 annually.[14] In total, the rebate rule could save Americans with diabetes $20 billion over the first 10 years of its introduction.[15]

But without decisive action from the Biden administration, self-interested middlemen will continue to pocket billions in discounts meant for patients.

PBMs and insurers defending the status quo argue that premiums will rise sharply if the rebate rule goes into effect. But actuarial studies show that's not true. A 2019 study from Milliman projects an increase in premiums of less than 1% — and that's not even counting the savings from reduced hospitalizations that would result from patients taking their medications as prescribed.[16]

In its final months, the Trump administration issued a rebate rule, making it illegal for PBMs to accept rebates unless these discounts are passed along to patients at the pharmacy counter. Many Democrats have long supported similar proposals.[17]

Unfortunately, as part of its across-the-board freeze — and also in response to Pharmaceutical Care Management Association v. U.S. Department of Health and Human Services, a lawsuit from the PBM industry challenging the rule — the Biden administration delayed implementation.[18]

Patients can't afford this delay. The rebate rule would help ensure millions of Medicare beneficiaries can afford their out-of-pocket costs and fill the prescriptions they need to stay healthy.

George Huntley is the CEO of the Diabetes Patient Advocacy Coalition and the Diabetes Leadership Council.

[1] https://www.healthcarefinancenews.com/news/extending-medicare-part-d-rebates-beneficiaries-would-save-seniors-29-billion-over-7-years; https://www.westhealth.org/resource/milliman-rebate-analysis/; https://www.pcmanet.org/wp-content/uploads/2021/01/2021-01-30-D.E.-19-Order.pdf.

[2] https://www.kff.org/slideshow/public-opinion-on-prescription-drugs-and-their-prices/, slide 7.

[3] https://www.shrm.org/resourcesandtools/hr-topics/employee-relations/pages/covid-pay-cuts.aspx; https://www.cnbc.com/2020/12/08/1-in-3-workers-faced-pandemic-pay-cuts-but-recovery-is-uneven.html; https://fas.org/sgp/crs/misc/R46554.pdf.

[4] https://www.sciencedaily.com/releases/2020/12/201218152733.htm.

[5] https://www.reuters.com/article/us-health-coronavirus-diabetes-insight/why-covid-19-is-killing-u-s-diabetes-patients-at-alarming-

rates-idUSKCN24P1B4; https://www.cdc.gov/diabetes/pdfs/data/statistics/national-diabetes-statistics-report.pdf; https://www.cdc.gov/diabetes/data/statistics-report/index.html.

[6] https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html.

[7] https://www.goodrx.com/blog/goodrx-list-price-index-rising-cost-of-diabetes-treatments/.

[8] https://www.americanactionforum.org/research/understanding-the-insulin-market/#_edn6 and Herkert D, Vijayakumar P, Luo J, et al. Cost-Related Insulin Underuse Among Patients With Diabetes.JAMA Intern Med.2019;179(1):112–114. doi:10.1001/jamainternmed.2018.5008.

[9] HuaX, CarvalhoN, TewM, HuangES, HermanWH, ClarkeP.Expenditures and prices of antihyperglycemic medications in the United States: 2002-2013.JAMA2016;315:1400–1402 https://jamanetwork.com/journals/jama/fullarticle/2510902 and https://www.businessinsider.com/insulin-price-increased-last-decade-chart-2019-9#.

[10] https://www.sanofi.us/-/media/Project/One-Sanofi-Web/Websites/North-America/Sanofi-US/Home/corporateresponsibility/Sanofi_2021_Pricing_Principles_Report.pdf page 6.

[11] https://www.healio.com/news/endocrinology/20190410/manufacturers-pbms-testify-to-broken-system-behind-high-insulin-prices.

[12] https://catalyst.phrma.org/nearly-50-of-brand-medicine-spending-goes-to-the-supply-chain-and-others?utm_campaign=Subscribe&utm_source=hs_email&utm_medium=email&utm_content=81706446&_hsenc=p2ANqtz--buT_QPtmYLEW5PSVjVK6Lu54v5McG2HHWuqi9YFDaLPKub_Te51FUc2VCnmDlGao2HuRT4rlxPcrmm9p4frpmLh6zgA&_hsmi=81706446.

[13] https://www.drugchannels.net/2019/04/the-gross-to-net-bubble-reached-record.html.

[14] https://catalyst.phrma.org/rebate-rule-would-help-ensure-seniors-with-diabetes-dont-pay-more-for-their-medicine-than-their-insurer.

[15] https://ihsmarkit.com/research-analysis/impact-of-passing-through-rebates.html.

[16] https://www.milliman.com/en/insight/mitigating-out-of-pocket-costs-for-insulin-users.

[17] https://www.pennlive.com/opinion/2019/03/democrats-should-support-trumps-medicare-rebate-proposal-opinion.html.

[18] https://khn.org/morning-breakout/biden-administration-delays-trumps-drug-pricing-rebate-rule-for-a-year/ and https://www.federalregister.gov/documents/2021/02/02/2021-02132/fraud-and-abuse-removal-of-safe-harbor-protection-for-rebates-involving-prescription-pharmaceuticals.

The Washington Post

Tackling cancer while battling the insurance system

Even plans that are supposed to save patients money can end up costing them dearly

When you take up residency in Cancerland, as I did when I was diagnosed with Stage 4 lung cancer in 2020, you regularly hear yourself described as "battling" cancer. With my one-pill-a-day biomarker-directed therapy, I prefer to say that I'm "tackling" cancer. But if I am at war, it's with an insurance system that works more like an extortion scheme.

In mid-January 2022, my phone rang early in the morning. This is my recollection of that call.

"Hi, this is Unintelligible Name from SaveOn."

"Who? I don't use Sav-On pharmacy."

"We're not Sav-On pharmacy, we're SaveOnSP, specialty pharmacy." SaveOn is pronounced exactly the same as Sav-On, just to be more confusing.

"I just changed insurers," I said, "and I've been in close contact with my new plan. They contract with Express Scripts, who've assigned Accredo as my specialty pharmacy."

"Yes, and we're your specialty pharmacy's specialty pharmacy. If you don't sign up through us you'll be charged the full amount of your co-pay of $4,500 every month for your specialty medication. We have all your information. You just have to verbally consent to let us manage your account."

I was stunned and so sure this was a scam call that I neglected to ask how they had arrived at this $4,500 co-pay, and how that could even be possible because that number was larger than my plan's deductible and out-of-pocket maximum.

"You'll receive a bill, but don't pay it," my caller continued. "Working with us ensures that you have a zero co-pay."

"Okay?" I replied. Was there a real choice? I've had lengthier consent discussions for a one-time hookup. I promptly forgot about the call and received no paperwork, but a few weeks later my monthly shipment of medication arrived along with an invoice from Express Scripts for $4,445. It noted that I might not owe this amount; nevertheless, it had a detachable payment slip, and a return envelope was provided. Remembering the caller's assurances, I tossed the bill into my ever-expanding, supersize file I've labeled "insurance gobbledygook." But when I visited an ATM the next day, my balance was significantly lower than I expected. $4,445 had been deducted by Express Scripts.

After I discovered that ginormous deduction from my account, I spent the majority of my waking hours that week ping-ponging between customer service representatives of my insurer, Express Scripts and Accredo. (The

name SaveOnSP appeared neither on my invoice nor on my account portals at Express Scripts and Accredo.) I was transferred so many times in my crusade to satisfy the gods that govern the peculiar ecosystems of customer service call centers — which require you to offer up your member ID, Social Security number, date of birth, Zip code and sacrifice of the first born, and shriek "operator" over and over into the void — that I can't remember which representative informed me that they didn't show me as being enrolled with SaveOnSP.

Nor was I enrolled, they said, in the co-pay assistance program I had been participating in for more than a year — one sponsored by AstraZeneca, which manufactures my medication, osimertinib, which is sold under the brand name Tagrisso. Like many pharmaceutical companies, AstraZeneca offers several types of assistance designed to help patients pay for costly medications. The program I'm enrolled in provides up to $26,000 per patient per calendar year for Tagrisso, which retails at $14,000 per month.

(A representative of SaveOnSP later told The Post, "Plan participants sign up independently with copay assistance programs, not through SaveOnSP; SaveOnSP monitors consenting participants' pharmacy accounts on behalf of plans.")

My previous insurer had billed the AstraZeneca program and the funds they received were applied toward my deductible, and my insurance plan covered the remaining cost of the prescription. When I switched over to Express Scripts, they had initially done the same. If any of the math seems like it doesn't make a lick of sense, it's because insurers work out deals with pharma companies that are closely guarded secrets. What's certain is that they're not paying the sticker price for drugs like mine. My plan had a pricey monthly premium, but I'd never been charged an out-of-pocket co-pay, and the system operated so seamlessly that I felt fortunate.

Many hours of my cancer-shortened life span were expended before Express Scripts agreed to a refund and acknowledged the screw-up. I was issued a provisional credit, minus a bank-processing fee that came out of my pocket, natch, and it took several weeks before the refund was fully secured.

I was able to weather the $4,445 debit, but more than half of Americans can't afford a $1,000 emergency. This could have had catastrophic consequences for another family who might have missed a mortgage payment or been unable to put food on the table.

Then, in mid-March, a representative from the AstraZeneca co-pay assistance program called me in a state of agitated confusion.

Previously, the program had been billed $250 a month in co-pay assistance for an annual total of $3,000; now it was being billed $4,500 every month. Had I changed insurers? "A third party is now adjusting my benefits," I said, and she got very quiet and stopped asking questions. Now I wanted to know what had happened and what I could expect.

As I would learn from longtime industry observer Adam J. Fein, founder of Drug Channels Institute, I'd been entangled in an increasingly exploitative scheme. In what's become a standard industry practice, pharmacy benefit managers (PBMs) contract with secretive third-party adjusters commonly called co-pay accumulators

and maximizer programs to process “specialty medication” prescriptions, including biomarker-targeted therapies for lung cancer and other chronic and deadly diseases. Once a plan engages a co-pay accumulator or maximizer, these entities reclassify these medications (some of the priciest on the market) as “nonessential.” This allows plans to exploit a loophole in the Affordable Care Act: Coverage can be denied for therapies that a plan labels “nonessential,” and a plan can reset the member’s pharmaceutical benefit deductible and out-of-pocket maximum to any amount of their choosing.

Accumulators typically first bill the co-pay assistance program up to a patient’s deductible, and then, because they aren’t obligated to apply this to the deductible, double dip and bill the patient up to the amount of their deductible before providing coverage, often with a newly inflated co-payment rate. “Maximizers are even sneakier,” Fein explained. “They extract the maximum amount allowable from the assistance program before the plan picks up the rest of the cost” ($4,445 turned out to be the maximum amount billable per month from my co-pay assistance program).

“Patients are generally unaware of the complex and confusing benefit design,” according to Fein. Sure enough, I discovered that my co-pay assistance was no longer being applied to my deductible. Had I missed a mention of this program in my insurance plans’ summary of benefits? Nope. The information packet I received included no mention of a third-party maximizer. So much for shopping as an informed consumer in the insurance market.

Making matters more opaque, companies don’t refer to themselves as accumulators or maximizers. SaveOnSP describes itself as a “cost-saving healthcare solution” that focuses on “helping plan sponsors and their participants manage the skyrocketing costs of specialty pharmaceutical drugs.” At the same time, PBMs are pushing back on growing concerns. In a web posting titled “Copay Accumulator Programs Level the Out-of-Pocket Playing Field,” Express Scripts refers to its “Out of Pocket Protection Program” as a way “to ensure an equal benefit for all members.” It reads, “Plan sponsors believe it is not fair to allow one member to utilize outside funding to satisfy their deductible while another has to meet it entirely with their own money.” That’s like complaining that one person has a wealthy aunt who contributes to their care and another doesn’t, pitting plan members against one another like a hunger games. The purported benefit of signing up through SaveOnSP was that there would be zero co-pay for my specialty medication, but I’d already had a zero co-pay — and now it would take me longer to meet my deductible and out-of-pocket maximum, which meant an outlay of more cash for my other health-care costs.

(A representative of SaveOnSP told The Post, “Drug manufacturers keep increasing specialty drug prices. Employer-sponsored health plans bear most of those costs. Plans hire SaveOn to implement plan designs that take full advantage of drug makers’ copay assistance programs and ensure plan participants get specialty drugs for no or little cost. SaveOnSP is glad that the participant received a refund for the pharmacy’s erroneous charge and got her specialty drugs at no cost.”)

I began hearing similar horror stories from patient advocates, such as Carl Schmid, the executive director of the HIV+Hepatitis Policy Institute. “To me, co-pay accumulators very much seem like extortion,” Schmid told me. “And they lead to a decrease in adherence since people can no longer afford their drugs.”

“What’s more,” he said — and this was something I hadn’t realized — “the out-of-pocket obligations patients must pay to meet their deductible and any coinsurance are based on the drug’s undiscounted, pre-rebate list price, not the pharmacy’s actual negotiated price.” Not that anyone knows the rates insurers negotiate; it’s a more closely guarded secret than the identity of Satoshi Nakamoto, but we know it’s substantially less than the sticker price.

Anna Hyde, vice president of advocacy and access at the Arthritis Foundation, wasn’t surprised by my experience. Ever since co-pay accumulators entered the marketplace in 2017, she’s been hearing from patients worried about “interruptions in care and whose co-pays were ballooning.” Hyde alerted me to H.R. 5801, the Help Ensure Lower Patient Copays Act, introduced to Congress in November 2021 by Reps. A. Donald McEachin (D-Va.) and Rodney Davis (R-Ill.) along with more than 50 co-sponsors. The bill “requires health insurance plans to apply certain payments made by, or on behalf of, a plan enrollee toward a plan’s cost-sharing requirements.” In plain English, this means money that plans collect from a patient’s co-pay assistance fund must count toward the patient’s deductible and out-of-pocket maximum. Fourteen states already have banned co-pay accumulators.

Alas, California, where I live, is not one of those states, and H.R. 5801 is still pending in the House. In late August, the HIV+Hepatitis Policy Institute partnered with the Diabetes Leadership Council and the Diabetes Patient Advocacy Coalition to file a suit challenging the US Department of Health and Human Services May 2020 ruling that allows plans to avoid counting co-pay assistance toward deductibles and out-of-pocket maximums. But the difficulties remain in place for now.

“It’s always a scramble,” sighed Lia (who asked to be identified by only her first name out of fear of retribution from future insurers), who lives in Georgia and was diagnosed with lung cancer at age 49. She takes a specialty medication that’s similar to mine, and when her current insurer engaged a maximizer she lost her deductible credit, which has had a dramatic impact on the family’s finances. She has another preexisting condition that’s most effectively treated with a compounded medication that isn’t covered under her plan.

“Each time we change insurances, I hold my breath,” she told me.
“And we know that’s not easy!” I joked. This is what we call “living with lung cancer humor.”

Not long after I spoke with Lia, I learned that I’d have to change my insurance once again. The kicker: SaveOnSP ran through my annual allotment of $26,000 in assistance in only six months, which means I could face a gap period of vastly inflated medication costs. How could I even prepare? When I phoned another insurer, I was informed that they couldn’t determine the cost unless I was already enrolled in the plan. The representative’s best guess was that I’d be responsible for 20 percent of the cost of the medication, up to $750 dollars per order.

“Okay, do you contract with a maximizer?”

“I don’t know,” the customer service representative admitted. Based on my experience, the information is so siloed it’s possible that she really didn’t know.

The Washington Post

Before collapsing into an exhausted sleep, I picked up my dog-eared copy of Yuval Harari's "Sapiens." I'd been rereading about ancient forager societies over the summer as a tonic to the slings and arrows of Cancerland contingencies. When an old woman in the Aché tribe, hunter-gathers who foraged the jungles of Paraguay, became "a liability to the band," one of the younger men would sneak behind her and kill her with an ax-blow to the head. *How far we've come,* I'd marveled during my first reading in 2015, long before I learned that the cells in my body were conspiring against me. Now, as I weighed my options, it hit me: I'm the old woman in the modern retelling of this story, and to a PBM, I'm a liability, so until science finds a cure, I can expect many more soul-sucking hours of haggling over insurance benefits. Sometimes, an ax to the head seems preferable.

# # #

March 23, 2022

Honorable Kentucky Senators,

On behalf of the undersigned patient advocacy and provider organizations, we encourage you to **support House Bill 457 as passed by the House of Representatives** on an overwhelming 88-3 bipartisan vote to protect and promote patient access to care across the commonwealth. HB 457, legislation sponsored by Rep. Steve Sheldon, is a commonsense solution for patients, providers and businesses that will address the harmful, profit-driven practices of pharmacy benefit managers (PBMs).

For far too long, PBMs have played an outsized role in the delivery and cost of healthcare – often dictating what Kentuckians pay at the pharmacy counter, which medications they can access and the amount pharmacists are reimbursed for their critical services. **HB 457 will improve Kentuckians' access to affordable, safe medications at the pharmacy of their choice.** And because HB 457 creates an open market where our pharmacies are competing to provide the best service and the highest level of care, patients would still have the option to use PBM-owned pharmacies if they choose.

Thousands of Kentuckians across the commonwealth rely on their community pharmacies for local access to personalized care. However, PBMs are putting many pharmacists' ability to practice at risk. PBMs routinely force patients to use mail order pharmacies instead of their preferred, brick-and-mortar community pharmacies while also forcing pharmacists to accept inadequate reimbursement rates for the medications they dispense. **These profit driven PBM practices are bad for patients, bad for the employees of our businesses and bad for Kentucky.**

We commend the General Assembly for its previous efforts to enact meaningful PBM reform. Unfortunately, the PBMs are committed above all to protecting their profits by circumventing your intent to improve affordable access to care for Kentuckians. HB 457 will finally put an end to these loopholes and ensure that we are putting the health of Kentuckians first.

Please vote YES on House Bill 457, as passed by the House of Representatives, and put the needs of Kentuckians over PBM profits once and for all.

Thank you for your leadership and attention to this issue.

Sincerely,

Accessia
Advent Health Manchester
American College of Rheumatology
American Pharmacists Association
American Pharmacy Services Corporation
Appalachian Regional Healthcare
Baptist Health
Coalition of State Rheumatology Organizations
Hemophilia Foundation of Kentucky
Ephraim McDowell Health
Kentuckiana Stroke Association
Kentucky Access to Care Coalition
Kentucky Hospital Association
Kentucky Independent Pharmacist Alliance
Kentucky Life Sciences Council
Kentucky Pharmacists Association
Kentucky Primary Care Association
Kentucky Society of Health-System Pharmacists
National Community Pharmacists Association
Norton Healthcare
Pharmaceutical Research and Manufacturers of America
Saint Claire Healthcare
Saint Elizabeth Healthcare
Sullivan University College of Pharmacy & Health Sciences
University of Louisville Healthcare
UK College of Pharmacy
Twisted Pink

<u>Independent Pharmacies:</u>

Alexandria Drugs
Anderson Apothecary
Apothecare I
Apothecare II
Apothecare III
Apothecare IV
ApotheCARE Pharmacies
Apothecare V
Avenue Pharmacy
B&B Pharmacy
B+H Apothecary
Blanks Pharmacy
Bluegrass Drug Store
Bluegrass Family Pharmacy
Booneville Discount Drug
Butler's Apothecary
Capitol Pharmacy
Clay Drug Store
Clinic Pharmacy of West Liberty
Corner Pharmacy
Crofton Pharmacy
Danhauer Drugs
Dixie Pharmacy
Dixie Pharmacy-2
Dixie Pharmacy-4
Dixon Drug Store
Etown Pharmacy
Eastridge-Phelps Pharmacy
Frazier’s Prater Drug
Fountain Square Pharmacy
Glenn's Apothecary
Glenn's Prescription Center
Good Neighbor Pharmacy
Grassroots Pharmacy
Harold Clinic Pharmacy
Hanson Family Care & Wellness Center
Health First Pharmacy
Heartland Family Pharmacy
Heritage Pharmacy
Hines Pharmacy
Hometown Pharmacy
Jamestown Pharmacy
Janes Pharmacy
Knox Professional Pharmacy
Lackey Family Pharmacy
LB Clinic Pharmacy
McDowell Professional Pharmacy
Med Save Eminence
Med Save Lagrange
Med Save Pharmacy
Med-Save Family of Pharmacies
Med-Save Legends
Med-Save Nicholasville
Medzone Pharmacy
Midway Pharmacy, Henderson
Nation’s Medicines
Owensboro Family Pharmacy
Parkway Pharmacy
Poole's Pharmacy Care
Princeton Drug Store
Professional Pharmacy
Radcliff Pharmacy
Radcliff Pharmacy
Roberts' Pharmacy
Ruwe Family Pharmacy
Ruwe Family Pharmacy Florence
Ruwe Family Pharmacy Latonia
Save-Rite Drugs
Save-Rite Family of Pharmacies
Scripts Pharmacy
Senior Pharmacy Solutions Medication
Springhill Pharmacy
Therapy Management Services
Sheldon’s Express Pharmacy
Smith Drug Company
Taylor Pharmacy
Thompson’s Pharmacy
Tom's Family Pharmacy
Total Care Pharmacy #3
ValuMarket Pharmacy
Weathers Drugs
Yates Pharmacy