

## PATIENT IMPACT REPORT: COPAY ACCUMULATOR PROGRAMS DOUBLE-DIP INTO PATIENT WALLETS

### The Double-Dip

Patients with rare and chronic illnesses often rely on manufacturer patient assistance funds to cover high out-of-pocket costs at the pharmacy. [But many insurers and pharmacy benefit managers \(PBMs\)](#) have implemented copay accumulator programs that **pay them twice** at the expense of the patient.

How does it work?

The insurer or PBM will apply the copay card to a patient's coinsurance or copay, but **not** to a patient's deductible.

**That means insurers get paid twice:** once at the pharmacy counter and once when the patient pays toward their deductible. This is especially stressful for patients who are increasingly enrolled in high-deductible health plans.

### Impossible to Reach Deductibles

In 2022, the average deductible was \$1,760. [That's double the average deductible in 2006.](#)

But out-of-pocket expenses can go much higher than that. For 2023 Marketplace plans, the [out-of-pocket limit for individuals is \\$9,100 and for families, \\$18,200.](#)

When and if a patient with a high deductible plan hits their out-of-pocket limit, only then does the insurer cover all of the patient's benefits, bringing much-needed financial relief to patients. **But when insurers refuse to apply patient assistance funds to the deductible, it puts the out-of-pocket limit further out of reach for patients;** a never-ending moving target that patients have to reach.

### Patient Assistance Runs Out

Patients can hit the cap on their patient assistance funds before the end of the year. This leaves patients stuck mid-year with the decision of paying a high price for their medication or going without it completely. For patients on fixed incomes, this decision is even more difficult.

### How is This Even Legal?

These shady practices aren't well publicized and take advantage of the nation's sickest. Copay accumulators unfairly place an outsized burden on patients, forced to endure financial stress compounded with the physical burdens of managing a chronic or rare condition.

## Actual Patient Testimonials

### Darla S. Bell

Congressional District: TX-03



*Darla relies on specialty medication to manage her condition and has been enrolled in health plans with high deductibles and premiums, making care expensive despite being insured.*

*Read Darla's story [here](#).*

"In 2019, though, things changed. At the beginning of the year, my online insurance patient portal originally showed my copay financial assistance counting towards my deductible. Yet when I logged back into the portal one month later, the information had changed to show the copay assistance had been reversed. **After countless and exhaustive efforts to get an explanation, a representative from the specialty pharmacy Alliance RX confirmed that Blue Cross Blue Shield of Texas had indeed adopted a copay accumulator adjustment program, leaving me responsible for the full deductible.**"

### Jess Wofford

Congressional District: PA-17



*Jess was diagnosed with Crohn's disease in 2007 and had her colon removed in 2019. She now lives with an ileostomy and depends on monthly injections to manage her condition. But in June of 2022, her patient assistance ran out.*

*Listen to Jess' story [here](#).*

(At 36:43) "One STELARA injection is \$24,000. A copay assistance program is available through the drug manufacturer, but people with government insurance do not qualify for this assistance. Luckily, I do have commercial insurance and qualify for the copay assistance, but the copay assistance program does have a limit which... in June [2022], I've already met. **What copay assistance program covers does not count toward my deductible so for every injection from June to the end of the year I will owe hundreds of dollars out of pocket.**"

## Kathi Luis

Congressional District: MI-09



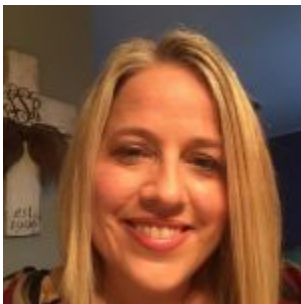
*Kathi is the Special Projects Director at the Amyloidosis Foundation, where she works with families who rely on copay assistance and are harmed by copay accumulator programs.*

*Listen to Kathi [here](#).*

(At 35:10) “Many patients and their families rely on copay assistance programs from manufacturers and non-profit organizations to afford the medications they need to manage their conditions. These medications rarely have generic alternatives. I’d like to tell you a short story about a patient we’ll call John. John called us when he found out that the benefit card he had received from the pharmaceutical company was not being applied to his annual out-of-pocket spending. This meant that he was still responsible for the same yearly amount. **He and his family knew they couldn’t afford the medication that he was prescribed at \$20,000 a month and still be able to put food on the table and live in the home they’ve lived in for 20 years. John has since quit taking his life-saving medication.**”

## Shannon Sharp

Congressional District: AL-02



*Shannon lives with X-linked hypophosphatemia (XHL), a rare disease that affects the bones. She began receiving a new treatment for the disease in 2016, but copay accumulator programs prevent her from affording this care.*

*Listen to Shannon’s story [here](#).*

(At 35:53) “My 20% coinsurance for one month’s treatment runs around \$5,000. Due to the many symptoms and complications of XLH, I am on many other prescription medicines as are most rare disease patients. As the year progressed, I began filling more prescriptions, my coinsurance continued to be applied. **I soon found out my out-of-pocket had not been met, nor were the payments from the copay assistance plan applied to my out-of-pocket.** The insurance company had begun using a new program called copay accumulators. In this case, the insurance company is getting paid twice. Once by the copay assistance plan, and once by me, the patient. This practice is called double dipping and is unethical and should be illegal.”

## Megan Starshak

Congressional District: WI-04



*Megan lives with Ulcerative Colitis. Access to an affordable health plan with adequate coverage for the care she needs is important for her, and has even factored into job decisions. She eventually found an ACA plan to give her the coverage she needs, but is aware that any introduction of copay accumulator plans could threaten her coverage.*

Read her story [here](#).

“...I still live with the fear of things being entirely disrupted - my plan might become unaffordable. **Copay Accumulators, should they come into effect in my state, might price me out of being able to afford a marketplace plan. They might stop covering my treatment, which has kept me in remission for 10+ years.** It’s a lot to think about. This tower could topple at anytime.”

## Pat Carroll

State: CT

*Pat lives with primary immunodeficiency and relies on monthly infusions.*

Listen to Pat’s story [here](#).

(At 30:17) “For patients like me with rare disease, that require costly life-sustaining treatment, copay assistance is our lifeline.

I understand that insurance companies and pharmacy benefit managers need to keep an eye on costs and encourage us to use less expensive drugs when we can. **But I have no option besides the immunoglobulin infusions. This isn’t a simple case of substituting a cheaper generic drug.** The Department of Health and Human Services changed the notice of benefit and payment parameters under the previous administration to allow insurance companies to implement copay accumulators.

These prohibit manufacturer copay assistance from counting toward our cost-sharing amount. We need federal legislation to protect us and allow the copay assistance plans to reduce our financial burden as the programs were originally intended.”

More patients stories from across the nation can be found on [PatientsRisingStories.org](https://PatientsRisingStories.org)

**Patients Rising Now advocates for access, affordability, and transparency in health care on behalf of the 133 million Americans living with chronic conditions. We believe that insurance benefit design should prioritize patient needs and provide value to those using their health care on a near-daily basis.**