

## Public testimony received by email for the 2022 annual public hearing on prescription drug prices

### *Email 1:*

Hello, I am a patient in Portland, Oregon. Thank you for this very informative report. I am sharing my story to support regulations - at both the federal level (the HELP Copays Act) and state level - **SB 560** - prohibiting insurance from implementing Copay Accumulator Adjustor Programs that do not count manufacturer copay assistance towards patient deductibles and out-of-pocket maximums. To date, 15 **states have enacted laws banning payer and PBM use of copay accumulator programs**. Oregon is not one of them. I would also like to support regulations that give prospective insurance consumers more explicit information on if these CAAP programs exist before enrolling in a plan.

I have been on Enbrel, a biological for rheumatoid arthritis, since 2015. This medication currently has a list price of **\$10,989** per month, a more than 800% increase from when I first got on it, with no change in formulation. This drug is a miracle for me, as I could not hold a pen for six years due to my arthritis before getting on it. Within weeks of starting treatment, I was 99% symptom-free. This is a first-line treatment for rheumatoid arthritis with no affordable alternative in the US.

I use manufacturer copay assistance to afford Enbrel. The list price is more than my monthly income, and I could not afford these drugs without copay assistance due to my high deductible. The only insurance available through my employer is an HDHP plan. For patients with high medical needs like me, these HDHPs are also helpful because they give us access to a tax-advantaged Health Savings Account, which many of us need for our medical costs.

In 2022, my plan implemented a Copay accumulator adjustor program mid-plan year. And my deductible went from being 100% met by my manufacturer's assistance to 0% met. I worked hard to get information on whether or not one of these CAAP programs was in place when I was shopping for a plan. However, I could not get any information from the insurance plans available to me, spending over 8 hours on the phone trying to get this information. There is no requirement that this is clearly disclosed to patients when shopping for a plan and no place on the marketplace to shed information on this.

Many patients like me were completely surprised in early 2022 to discover that we had used up 100% of our copay assistance allowance (mine is \$12K per year) because none of it was getting applied to our deductible. So I was paying the full amount of my drug each month with copay assistance as there were no guardrails. It was exhausted in a month.

Until a July 2021 HHS ruling, insurance companies and PBMs weren't allowed to do copay accumulator adjustor programs for **\*\*drugs with no cheaper alternative\*\***. Protecting the patients like me. This is not about buying a brand name of Tylenol when a generic is available, like a compound drug. Most of these specialty drugs have no cheaper therapeutic equivalent.

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I already face numerous barriers to accessing this drug - I was required to fail first on three cheaper drugs before being approved for this drug, a process called step therapy. Every year, I must race to get prior authorization in a process that can sometimes take longer than the 28-day quantity limit I have on my drug.

This CAAP program adds an additional barrier. My insurance exhausted my \$12,000 annual limit for my manufacturer copay assistance and then also charged me the full amount. I went from 7 years of paying \$0 per month for my drug to unexpectedly owing \$3,000 for a single month's refill. Copay accumulators are a new form of surprise billings.

The insurance companies also are not required to disclose these policies are in effect when shopping for the plans (just in plan documents for already enrolled members, where there is no standard language for them, and the language is confusing). In most states where they are not banned, 80-100% of plans on the marketplace have them in place (AIDS institute report has details on this).

It sucks as a patient who has been on these drugs for years because many of us choose our insurance plans based on manufacturer assistance we have used for sometimes decades - so we choose high deductible plans because we meet them using copay assistance in Jan or Feb due to the high costs of our drug and the rest of our in-network medical costs are no out of pocket.

Studies show patients are far more likely to abandon their treatment when out-of-pocket costs exceed \$100.

The bipartisan HELP Copays Act requires health plans to count the value of copay assistance toward patient cost-sharing requirements. Regulation would require private plans to count all cost-sharing for covered services to accrue to a patient's deductible and out-of-pocket maximum.

The HELP act also closes a loophole that allows many employer health plans to deem certain covered drugs as "non-essential," which means that the insurer will not count any cost-sharing toward the patient's deductible and out-of-pocket maximum.

Here is the podcast episode all about my experience:  
<https://armandalegshow.com/episode/swimming-with-sharks/>

Lillian K.

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### **Email 2:**

Dear DCBS,

I want to thank you for hosting the drug pricing transparency webinar today. I am a well-informed Executive Director of a chronic disease advocacy organization and truly appreciate that you hold this informative webinar each year.

The variety of speakers and panels included in the webinar were very interesting and informative. I made the comment last year and would reiterate the comment again this year, advocacy organizations are the people who represent the patients, those actually using the services and medicines talked about during the webinar. It would be appreciated if one of those organizations, or someone representing a coalition of those organizations, was invited to participate on one of the panels as well. The gentleman who spoke for the pharmacists was amazing! I think the actual participants of the programs and services offered provide insight on the entities that no one else can provide. The final testimony from the woman with chronic disease was incredible and relatable. Many in our organization face the challenges she described. I think she represents a large portion of all patients in Oregon.

I also appreciate the legislative recommendations offered for the coming legislative term. I completely agree with more PBM oversight. I think we saw and heard today that PBMs add costs to the system rather than save money for the patient, as they claim. My own personal story with PBMs is exactly the opposite of them being helpful. I am happy to share my personal thyroid medication story and my family's bleeding disorder challenges with medications through PBMs. Our experience is that they are forever increasing prices or changing meds to get a higher rebate on a name brand rather than offering the cheaper generic.

However, I would caution about the need for transparency of patient assistance programs from the manufacturers. While you'll probably see a huge amount of money going out for patient assistance, because OR does not ban the accumulator adjustor/maximizer programs, that patient assistance is not going to support patients in OR. That patient assistance is going to support PBMs and insurance companies. For example, our family, we only need to collect \$5000 from patient assistance programs annually to cover our out of pocket costs but because our PBM, through our employer insurance, has an accumulator, they can collect up to \$90,000 in patient assistance from manufacturers on our behalf and we still owe \$5000 to meet our out of pocket costs for the year. So, to be VERY transparent, you need to ask how much of the patient assistance actually goes to PBMs and how much patient assistance actually goes to assist the patient. I think the data will be skewed and look like the manufacturers pay out millions in patient assistance but the sad thing is that very few patients benefit from that assistance. Just a word of caution.

Again, thank you so much for today's webinar. I appreciate working with DCBS every year on many programs offered through Pacific Northwest Bleeding Disorders (PNWBD). We appreciate your hard work.

Thank you,  
Madonna M. S.

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