

Oregon Drug Price Transparency Program – 2025 annual report exhibit

Exhibit contains stories and comments from consumers received by DCBS through Nov. 23, 2025.

Note: The following has been lightly edited for readability and length. Names of consumers and family members and other private information have also been removed.

I'm close to being 100% Medicare. Right now I'm retired with A&B, but my wife has private insurance and that covers my current medications. I am on a biologic for psoriatic arthritis (Simponi Aria) that is on an infusion schedule for 6 times a year. I have recently found out during the open enrollment periods that it is not covered by Medicare Part B, and not covered by C or D either. Medicare Part B covers some of the cost of the infusion itself, but not the medication.

To say this is upsetting is mild. My wife had to keep me on her insurance this year because I don't have a resolution to get the care I need being on Medicare alone. I could not find one plan for Medicare Part C or D that would cover this medication. I also spent several hours just trying to find this information looking at several Medicare Advantage plans, and that was about as much fun as a root canal without pain medication.

PS: I'm sick of American healthcare. Metaphors intended.

In 2024 I had a high deductible health plan through Regence Blue Cross Blue Shield. I have been on the same generic drug for years, and it usually costs \$4 for 90 days, filled through their contracted pharmacy Express Scripts. The explanation of benefits says the Express Scripts billed Regence \$10, and I paid \$4. Due to a job change, I now have a similar high deductible health plan, but now through Premera Blue Cross Blue Shield. Premera uses the same pharmacy, Express Scripts. The explanation of benefits says Express Scripts billed Premera \$528 for the same generic medication, and I paid \$62.

The change is just so large that it really caught my attention. I would also state that prior to switching health insurance, I was told by Premera and Express Scripts that they could not give me an estimate of how much my daughter's prescription would cost. It was very hard to make decisions, and I had to just add her to my new insurance plan and hope for the best. This is not great, since the cost of this medicine ranges from \$50 to over \$600, and it is totally unclear why there would be a range like this. In the end, they told me to look at their drug schedules. When we ran the Rx through their pharmacy, Express Scripts, it cost \$442, different than what their drug schedule said, and then through Safeway it cost \$50, also different than what their drug schedule said. I am finding this confusing and not transparent.

Last night I called my Aetna Insurance and spoke to the pharmacy. I asked what my meds would cost me next year. This year for a 3 month supply of Repatha was \$432 at Fred Meyer (Kroger) that I picked up. The Aetna pharmacist looked up and said transfer your prescription to Walgreens, it will cost you \$249 there. She verified it was also 3 months' worth. That's \$183 difference! WOW!!! How can Fred Meyer get away and over charge like that! *[Note: Insurance and PBM pharmacy networks may have different levels or there could be other factors that lead to a difference in patient costs.]*

When I did not have OHP (*Oregon Health Plan - Medicaid*), I would regularly drive to Canada to pick up this medication, where it cost \$7.50. The cheapest price I am able to find it for here with insurance is \$113.85 for Pregnyl. This drug has been FDA approved since 1939 and is available as a generic in most countries. Entire studies have been written about the insane pricing of this specific drug. Reference from consumer: "Variations in the Retail Price of Human Chorionic Gonadotropin in the United States," J Miller, M O'Leary, D Schneider, C Loeb, L Jenkins, F Yafi; The Journal of Sexual Medicine, Volume 20, Issue Supplement_1, May 2023.

I did not authorize to be charged \$80 for the same quantity of medication I have previously purchased for \$40 or \$25. I called Express Scripts to try to resolve this, and was told that their policy is to charge more if the doctor's prescription is for 35 days instead of 30 (even if it is the same size tube).

It's fishy to me that the insurance company is setting a price of \$1,343.40 for tadalafil which is something I can buy for \$20.

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Previous co-pay for same drug/same dosage/same insurance was \$31.46. Confirmed with staff and on my invoice that doxepin hydrochloride went from \$178.60 on 2/4/25 to \$419.60 on 7/31/25 (fulfillment date). I want to ensure that real data is being collected about drug pricing to counteract the lies from the current administration that they are lowering drug prices. I would be happy to share my full invoice/receipt to help build the data set on the impact to drug prices.

My insurance copay would be \$230 for pantoprazole sodium, if I pay cash it's \$27. Thankfully my local independent pharmacy was willing to share the details. Insurance pharmacy benefits programs only exist to save insurance company's money and extract higher copays for their shareholders. An inappropriate extraction layer for consumer's hard earned dollars.

The cost increased from my order for dextroamphetamine and amphetamine sulfate to when it was delivered. I have a screenshot to prove it. On my checkout screen and submitted order, it totaled to \$9.91, but the actual charge I saw after receiving the meds was \$49.56.

I can only speak of my one medication Adderall. It seems I can get it covered by them when my life is coming back together. Then I lose my medical, and I've got to pay out of pocket \$200. When I don't have that kind of money, my head says go get street drugs. And that's all I can tell you. Usually I am never able to get the meds I need because my brain is a mess and leading me down a very bad road.

My insurance coverage didn't change, the retail price listed on the pharmacy label didn't change, just the cost at CVS for dextroamphetamine and amphetamine sulfate. It doubled. I know \$5 to \$10 isn't a wild price, but a 100% increase is way higher than inflation.

I am covered by Fedblue Blue Cross Blue Shield, which covers my prescription drugs. CVS, the pharmacy mail order, has a formulary of allowed drugs with Gemtesa present, but not approved. There is, however, an exception form for the prescribing physician to ask for a prescription to be allowed. My primary care physician has submitted a prescription for Gemtesa 75 mg per day. As requested, he submitted the formulary exception form by fax and it has not yet been accepted. I am extremely frustrated by this lack of trust in my physician. I am a physician myself, and I see no acceptable reason to deny his authorization for this drug, which he has found effective when others have failed, and has helped a friend of mine greatly. I have used both tolterodine and oxybutynin with no perceptible effect and must insist on being allowed to try Gemtesa.

I'm being charged a co-pay for metoprolol succinate, despite being on OHP Plus (*Oregon Health Plan - Medicaid*).

My cost for NP Thyroid, which is a generic desiccated thyroid medication (desiccated thyroid meds were developed a good century + ago) has gone from less than \$30 for a 90 day supply to \$144 this year. Regence will no longer cover any desiccated thyroid medications at a more affordable price point. Generic synthetic thyroid medications are the only ones they cover on tier 1 (Armour and NP Thyroid are tier 3 now). The price with insurance is the same as without insurance. In fact in some cases with insurance is more expensive now. Synthetic thyroid medications do NOT work for me, they were less effective and caused intolerable side effects.

There is no rational justification for the cost increase. The medication was developed over a century ago. The brand I use is considered a generic. This is purely Regence trying to dictate how I'm treated via financial stress. I don't have the choice to switch to their "preferred treatment," I used it in the past, and it was ineffective and caused horrible side effects. They do not cover any other options of the same type of medication (natural desiccated thyroid) at a better price point.

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I have dry eyes and use Restasis eye drops, in addition to getting tear duct plugs every 6 months. Restasis is an old generic drug, but Restasis puts it in small dropper vials and somehow must still have a patent for that. I have a Medicare Advantage plan, but even with that my copays are \$250 per month (40% of the cost, which would otherwise be \$625 per one month supply).

I called the insurance company, Providence, about this and was told, although there is a generic available in some form, the cost to me would be even higher than for the brand name, Restasis vials. So, I save the vial each night and use it twice even though the directions say not to do that, and can usually get by with getting my prescription every other month. I have been using the Restasis for probably about 25 years and the cost was initially high, but not nearly as high as it is now. It is unbelievable that the chemical in this drug, which apparently is some kind of immune suppressant, has existed for a long time, yet this drug is so expensive just because it is in little vials.

I don't know how anyone with less income than I have could possibly afford it. I am told that without adequately treating my dry eyes, I would get corneal damage since I already have Fuchs' dystrophy.

Thank you for listening. Here is my story. I started antidepressants between my 30's and 40's. Was on one or another for 10 yrs, a brand or formula would work for a time, but lose efficacy after a short (or longer) period, depending on the chemical makeup of the prescription. The one medication that worked well consistently was Wellbutrin. Not the generic. For a while I was on a program that made it affordable. When the program was discontinued, the price for non-generic shot up to over \$2,000 a month.

The price would come down some if I got a 90 day supply, but there was no way I could afford it. It was not on the insurance prescription drug formulary, so if I wanted to appeal to have them cover it, I had to prove I had failed all other medications that were approved for that. At the same time, I was to be seen by a licensed mental health provider with therapy regularly, which added on to costs with copays. I ultimately gave up on getting brand-name Wellbutrin.

With the help of a naturopathic physician, I was able to manage my depressive symptoms. I use small doses of cannabis to help process more difficult times. The naturopath helped me incorporate diet, exercise and meditation that has been more effective than Wellbutrin ever was. I speak up today because not everyone has the opportunity to find alternatives to their prescriptions. It's a horrible feeling knowing you can't get an effective medication because of the price. Insurances can be very cold-hearted around paying for things they aren't contracted to. The price was excessive and there was nothing I could do to be able to obtain it.

At least a dozen people sent the following message:

Oregonians Need Relief from Rising Rx Prices!

To the Oregon Drug Price Transparency Program Managers:

Thank you for focusing on prescription drug prices. We need action today. Too many Oregonians cannot afford to buy groceries AND fill the prescriptions they need. This situation cannot continue. We all deserve access to affordable health care, and that includes medications.

Please do everything in your power to address unreasonably excessive costs and hold Big Pharma accountable.

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While searching for Medicare Advantage options for 2026, I found that, even for the same insurance company and same retail pharmacy, prescription drug prices vary by plan chosen. For example, United Healthcare's explanation is that drug prices vary based on the "network" providing the drugs to the pharmacies. I assume that means the Pharmacy Benefit Managers (PBM's), which I understand are also owned by United Healthcare.

I also read that a study of insulin costs showed that, of the difference between the cost from the manufacturer and the price to the consumer, 80% was represented by "rebates" to the PBMs. I thought PBMs were created to manage and lower cost to consumers, but it appears they are just another source of profit in the pharmacy world.

The cost of my medications will be a choice. Purchase medication that is needed or pay rent.

I have extensive, direct experience with the business side of drug marketing and pricing trends. During my 23 years working in the pharmaceutical industry, I held executive positions which included bids and contracts, pricing intelligence, group purchasing organizations, etc. My driving force has been to reduce healthcare costs safely, knowing that our U.S. system is unsustainable, unfair, and an economic trainwreck.

My story began as an undergraduate. In my studies of the healthcare system in general, with a special focus on the pharmaceutical industry.

My perspectives span 52 years. Over those years, I've participated in the various trends to reduce costs when we, as a country, began to recognize that, frankly, as experts have reported, our for-profit healthcare system is a failure. People are getting older, sicker, and just can't afford the raising prices.

Even though I believe this mess is of our own making, all is not gloom. There are specific strategies our country should take, and Oregon can take, to ease the pain. I'd welcome the opportunity to offer them at the hearing.