

Oregon Drug Price Transparency Program – 2024 annual report exhibit

Exhibit: Stories from consumers received by DCBS through Nov. 27, 2024

NOTE: There is light editing for readability and length. Names of consumers and family members and other private information was removed.

More than two dozen people sent the following message:

To the Oregon Drug Price Transparency Members: 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.

I have been on this medication for 38 years. It helps with sleep and dizziness, it stops dizziness, and it works. Now it's even harder to get this medication. My body does not adjust to other medications. Stopping medications puts people's lives at risk. This medication helps me live. I was born with vertigo and let me tell you, this medication works for me. I tried other medications that did not work for me. I need this medication to help me live and do normal things. This is my concern, that medications that are hard to get is not right. It harms people's lives and puts us at greater danger. Also copays to doctor and copays to medication when one is low income is another concern. How are we elderly people going to live with all these copays to doctors and pharmacy?

I work for a medical insurance carrier in Oregon and would like to retire, but continue working just for the prescription drug coverage. I am diabetic and on multiple medications. Every time I hear how politicians have helped by capping the amount an insured can be made responsible for on insulin, it makes me mad.

They haven't fixed the root cause of the problem by forcing the drug manufacturers to charge more realistic fees; they've just passed on the problem to the insurance carriers who in turn build that into the rates. While I appreciate the lower cost, politicians should be focusing on the real problem. Drug manufacturers seem to be able to charge what they want and are immune to accountability.

Eleven years ago, I was diagnosed with ulcerative colitis and Crohn's disease. After various treatments I was placed on a biologic to be infused every eight weeks. This medication had been around for 25+ years for treating this, but still cost approximately \$14,000 for just the medication, not including the IV and the skilled nurse to administer it. Several years later, my insurance would no longer cover this medication, and my doctor HAD to switch to an alternative biosimilar. This switch impacted the pharmacy that distributes as well as the nursing staff allowed to administer it; this was a major switch having to start from scratch and hoping I didn't have a negative reaction to this biosimilar.

The biosimilar medication was/is the same cost, plus all other associated costs to receive treatment. This is a lifetime diagnosis. I have at least 40 years with treatment every eight weeks, unless a cure is found.

The pharmaceutical companies have a program that covers ALL but \$5 of the medication, this is after what the negotiated price of the medication with the insurance company has been bargained and padded by insurance. That is still \$12,000 that the program reduces to \$5 out of pocket. Which is great; however, why don't the pharmaceutical companies just price the medication to \$5? This impacts the overall cost of coverage with insurance.

At any time, these programs may disappear, the insurance companies may drop coverage. If the insurance programs change drastically in the future, I may even not be able to get coverage because of my pre-existing condition. Hopefully this never comes to pass.

I have been dealing with three different cancers for the last five years. One is in a watch mode and doesn't require any medication at this time and one cancer is in remission after surgery, thankfully. The third cancer has been a bit of a struggle. It keeps coming back and has now spread to another area. Since my body has resisted the current treatment my doctors are looking at a chemotherapy treatment for as long as it is working on the cancer.

I started researching the chemotherapy drug Lenvima, and my cost out of pocket is \$2,100.00 a month. I don't know what my insurance company pays for this. But I have been kept up nights worrying about how I

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am going to pay for this. I have spent hours on the phone with different organizations that offer assistance to people who are having issues with paying for medications.

Both my wife and I are on SSI and after we pay our monthly bills we only have a couple of hundred dollars left over. I know it cost money to develop these life-saving drugs, but at what cost to the people who have to take them to stay alive? If I don't pay the mortgage, I don't have a roof over our heads. We would end up homeless. Something has to change to make these more affordable. Thank you for your time.

As a patient coordinator for a rheumatology group, one of my primary job duties is to help patients while we unravel the complexity of each insurance in an effort to get the medication their provider wants them to take. We navigate the obstacle course of step therapy requirements set by insurance companies in an effort to control the medications and treatments instead of allowing providers to practice medicine. Often our team will spend weeks or months trying to fight with insurance, while the patient remains in flared disease state of autoimmune diseases such as rheumatoid arthritis, gout, psoriasis, lupus and many more.

Just this week, PacificSource insurance denied the only medication proven to be safe for pregnant or nursing mothers, Cimzia, to a nursing mother because they want proof she hasn't tried and failed medications that impact her liver health and are directly transferable to the baby.

If we are able to prescribe the "first choice" medication, I then help the patient with the next hurdle, affordability. Most drug manufacturers have copay assistance for biologic meds because of the cost, however insurance companies, like PacificSource and Regence, are adopting policies that exclude the use of a copay card to meet the out-of-pocket max. This means that "Chris" will fill their Humira with the pharmacy at a copay of \$4,500 using their copay card provided by Humira, only to find out after two months of billing cycle that the pharmacy has reversed payment from Humira and is now charging them \$9,000 because the insurance has told them to, saying the copay card isn't allowed to pay toward out-of-pocket limits. Now Chris has a bill from the pharmacy for \$9,000 and has not made a dent in their \$10,000 out-of-pocket maximum.

Patients should be able to get the medication their doctor thinks is best for them, use any assistance available to pay for it, and live a pain free, disease controlled life.

I'm a senior. Since I've recently been approved and now receive SSDI, I'm now on Medicare. Paying for my scripts instead of the insurance covering the costs, takes away money from other necessary things like food, over-the-counter medicines, and everyday household items. The increase in medicine costs, have made a negative impact to my budget. My food stamps have been reduced as well, so the funds used to pay for meds now means less money for those other items and less for food.

It seems one way or another the "system" and those who make these policies just want to keep the poor struggling to make ends meet. We pay enough over the years for insurance coverage, but they continuously want more. As a senior citizen, it would be spectacular to have a "system" that actually treats its seniors with respect and care.

My sister, who lives in Portland, was visiting me in Medford when she tested positive for COVID-19. Her Portland physician prescribed Paxlovid, sending the prescription to my pharmacy. My sister initially provided out-of-date Part D insurance coverage. I was informed that in order to pick up the Rx, I would have to pay \$1,600 or provide different insurance coverage. We eventually got my sister's current insurance information and the cost was \$0.

I need opium tincture to be able to leave my home due to chronic diarrhea due to surgery that went wrong and losing a lot of my small intestine. I have had this prescription for 14 years and my doctor has to call in for every refill. This drug does not get you "high" at all. It just slows down your gut so you can live a normal life. I have gone into the pharmacy to get my prescription and been told they didn't carry it any more. This is so

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scary when I only get enough to get me month to month, and I hear it might be days now before I can find a pharmacy that has it.

I've had to change pharmacies over six times, because it's hard to find a pharmacy willing to carry it, as it has the word "opium" on it. Anyone who has had diarrhea has to just imagine what their life would be like if they didn't have a drug to control it. It's scary to think that one day I may have to be housebound. And even with this drug, I'm still in the restroom up to 10 times a day.

And the price! I have insurance but still have to pay \$195 copay per 40 days for my prescription! My last pharmacy would give me 30 days for a \$95 copay, but the pharmacy I go to now, says that they can't open the bottle that holds 40 days in it and give me just 30 days, so I am stuck paying about \$90 more for just 10 more days. Because they say they have to distribute the whole thing (by law). I don't believe that, but I don't argue because I need that medicine.

In 2022 I paid \$20 per prescription. In 2023, that went up to \$30 for no reason other than it was 2023. Now in 2024, the same prescription is \$40, so it has doubled in just over a year just because the calendar changed. Same medication. Same amount. Same person. Pure profit for someone other than me.

I retired from the practice of medicine in January 2022. Little did I know that one of my medications called apixaban or Eliquis would cost over \$600 per month. Fortunately my insurance brings that cost down to \$240 a month. Because of IRRMA (where Medicare is more expensive based on tax reports from two years previously) and the cost of this medication, I decided to take Social Security at age 63. I really don't know what would happen if I was single. So I was in a double bind: continue to take money from my IRA to pay for meds but continue to pay for IRRMA, or rely on savings. The point is, I am a retired M.D., and I struggled and continue a bit to struggle.

I have been overweight my whole life. The first time I weighed myself and felt crushing disappointment about the number on the scale, I was 11. My well-meaning parents encouraged me to diet, start seeing a personal trainer, etc. Thus began my perpetual dieting that would eventually lead to a full-blown eating disorder in my teens and early twenties.

I did achieve some meaningful weight loss in that time, but at the expense of my mental health and due in no small part to a cycle of restricting, binging, and purging. Eventually I realized the harm I was doing to my psyche and body with the eating disorder wasn't worth the weight loss I was seeing. I decided to seek help. It took years of very expensive therapy and hard work on myself, but I have been in remission for anorexia and bulimia for close to a decade now.

As proud as I am of that, and of the healthy lifestyle habits I've worked hard to make my new baseline, the weight has steadily crept back. It's disheartening to know that I've put in so much work but my body still betrays me daily, and that little nagging voice in the back of my head starts to amplify: "you could always restrict and purge again."

For so long, I couldn't understand how I could be doing everything "correctly" — exercising 3-5 times a week, cardio and weights, eating in a calorie deficit, prioritizing lean proteins and fiber, cutting out alcohol — and yet my weight would not budge. Enter GLP1s.

Last year, I finally found a doctor that suggested we treat my obesity as what it was: a chronic disease. She recommended I try Ozempic. After wrestling with the idea of "cheating" or "taking the easy way out" I was finally convinced by her that it was not in fact a moral failing on my part, but in fact a misfiring biological mechanism that kept my body from losing weight. The emotional catharsis of having a health care worker look at my weight and for the first time tell me that it wasn't my fault. That I wasn't a lazy slob who just needed to "eat less and move more" but in fact, I was suffering from an untreated chronic illness. I've never felt so validated in all my times visiting a doctor.

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After climbing the mental hurdles, the elephant in the room was the cost. GLP1s are ridiculously expensive. I was very fortunate that my provider could start me off with sample pens for the first four months, but once I needed to increase my dose, and switch to Zepbound, I was on my own. And unsurprisingly, my insurance does not cover these medications. Even with a manufacturer discount card, my monthly prescription costs \$550/month. Without the discount it would be \$1,300/month.

I am fortunate enough to have a family support system that helps me cover these costs, but I still feel the looming anxiety of possible changes to the discount card, or changes in my family's finances. If I were to lose either, there is no way I could afford a full-priced monthly supply of Zepbound.

On these medications I've seen 60+ pounds of weight loss without slipping back into an eating disorder, and it's felt easy. I've healed my relationship with food. I've strengthened exercise routines and reinforced my healthy eating habits. I still have weight to lose to get to a truly healthy weight for the first time in my life, but I worry about my ability to access this amazing medication as a key tool in my weight loss journey.

I also can't help but think about all the people suffering from obesity for whom these drugs are simply not an option. It's unconscionable that we have created these drugs that so effectively treat a chronic illness that a significant portion of the population suffers from, and we've effectively put them behind an insurmountable pay wall. There's no reason these drugs should cost as much as they do. They cost under \$50 per dose to the manufacture, and that's being generous. It's simply greed that keeps these drugs expensive. Greed reinforced by a societal stigma against obesity and a misguided and outdated notion that it is a moral failing to be obese. It's not. It's a chronic illness and those suffering from it do not deserve to be price gouged for treatment or ostracized for seeking treatment.

I am a licensed professional counselor in central Oregon and would like to share experiences on behalf of my clients who have trouble getting prescription medications filled due to cost or lack of availability.

Mental health medications are vital to a client's overall health and well-being. Without these medications, clients tend to experience more severe anxiety and depression; challenges at home, school, and work; and a decreased ability to utilize important skills they have gained in therapy. When clients run into trouble getting insurance approval for the medication they need or when the medication is back ordered, this becomes a very real hardship for them. Some clients will finally break down and pay the, typically, high cost for their medication, but this brings increased financial burdens and trouble paying for other things, like groceries and bills. When this cycle continues, the client becomes stuck and their mental health continues to decline.

Access to affordable medication continues to be an issue in the mental health field and across other fields as well. Many of my clients have additional medications for other health issues, and the inability to purchase these medications will in turn impact mental health as well. It's an awful cycle, and I hope the mental health aspect can be taken into account when lobbying for more affordable drug prices.

Low Rx drug user which is cheap if I pay for an over-the-counter version without insurance. With insurance coverage, it's three to four times more. I was given a script for a one-time new drug for a colonoscopy. I went to have it filled and was stunned at the cost, several hundred dollars with insurance. The pharmacist explained it was due to insurance company drug middlemen.

She removed my coverage from the pricing and the cost dropped by almost 80 percent. Absolutely absurd that folks, particularly without much economic knowledge, get ensnared by this. The local pharmacy isn't helped either. I know this is partly a federal issue, but I have zero expectation they will fix this. Not sure what the state can provide, but this issue must be keeping people from getting care or creating economic hardship in other parts of their budget.

I would like to share my story from a pharmacy perspective. Smaller pharmacies are closing at an unprecedented rate. Fewer pharmacists are enrolled at schools, and we already have a shortage of both pharmacists and technicians. There's a push to unionize across the industry, and we're not only seeing strikes and walkouts, we're seeing pharmacies closing for a day, a weekend, or shortening their hours with

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no notice due to lack of staffing. This is going to get much worse in the near future without some drastic changes in health care.

Pharmacy benefits managers (PBMs) are making millions of dollars annually to the detriment of doctors, patients and pharmacies. They are putting demands on us that siphon off our time and our profits along with medical staff that prescribe. My physician closes on Fridays now, just to deal with the excessive and unnecessary requirements of insurance companies and PBMs. We spend a large portion of our time fighting for our patients' right to get the medications that they need, paid for in a timely manner. And we see, on a daily basis people going without, or waiting for weeks to get their meds.

For example, we are now required to get clarification from the prescriber, on every cream, lotion, ointment, etc., as to how much is used, and how long it should last. The doctor cannot just write it in as a 30-day supply. They have to include how many grams per dose or per day, and the site of application. If we don't get this information on the Rx, we can get audited, and they can charge us back for every time the patient has filled it. My pharmacy has at least 25 prescriptions right now, where we are waiting to hear back from the office, and the patients are not getting their topical meds for sometimes weeks, because the offices are overwhelmed with these details that should be between the doctor and the patient.

When an eye drop is needed, different insurers have different ways to measure the amount, and how long it should last. They require this specified in "drops per milliliter." Yes, your insurance company may allow 16 drops per ML, and your neighbor gets 19 drops per ML. There's no allowance for an elderly person with a shaky hand that misses their eyes on a regular basis. So seniors are going days without the eye drops that allow them to see clearly or treats their disease, because the insurance response is that it's a "refill too soon" and that they'll pay for it again next week.

Insulins are very expensive. Although proper insulin treatment requires differing doses in response to the blood glucose test, weight, exercise, diet, and illness, your insurance company limits the amount, and we have to count the calibration units on every dose. If the doctor writes that you're using 50 units daily, but doesn't specify that it's divided into four shots a day, you're going to run out before they will pay for it again, because you're using an extra 10 units a day to calibrate four shots. If you're sick and not exercising, you'll need more insulin, but the doctor will have to write a new Rx for a dose increase or you'll run out before insurance will pay.

Medicare will pay for supplies for three daily tests, if you're using insulin, and one daily test, if not. I have to explain to both patients and prescribers all the time, that yes, as a newly diagnosed diabetic you should be testing six times a day to establish a pattern and learn how to get it under control. But if you have to pay \$100 out of pocket for a box of test strips and \$20 for lancets, you're not going to be testing at all. And if insurance requires a "prior authorization" (PA) for six-times-daily testing, it may be another week before the paperwork goes through. By then, you're going back in the hospital. If the Rx doesn't have a diagnosis code, the doctor's NPI (national prescriber ID) or specify whether or not you're using insulin, they won't pay. Can't the doctor just call and give us that information? Can't we just look to see if you get insulin? No! It has to be written on every single Rx every single time. If we don't have a copy of your Medicare card and a signature on several Medicare specific forms, they won't pay.

But that's just Medicare. If you're on Medicaid you can test more often ... you and your doctor actually get to decide. So long as it's on a FreeStyle Lite device that only works with FreeStyle Lite strips and lancets. Why? Because they've contracted with FreeStyle and won't pay for anything else. You lost your job and are temporarily on Medicaid? Now your doctor has to send in three new prescriptions for the FreeStyle meter, strips and lancets, with all the correct information, and you have to learn how to use the new meter. You changed jobs and have a new insurance? Well, your new insurance is contracted with OneTouch, so we'll need three new prescriptions for that. The numbers on your new meter are too small for you to read? Your doctor can get a prior authorization for a low-vision "non-preferred" meter and write three more correct Rx that will take a few more weeks. Why won't they pay for any meter? They signed a "preferred" contract with

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OneTouch and get a lower price by doing that. So you get it cheaper? Well no, they keep the extra money and also their top executives get a bonus (kickback) for every Rx while you go days or weeks without testing and your disease does unseen damage to your body.

There's a record number of drug shortages right now. We do everything we can to keep every drug our patient's need in stock. One month, we can't get anything but brand-name Adderall, the next month we can't get any of the generics. I actually had a patient drive from Bend to Salem just to get her generic Adderall because she isn't able to function at work without it. We are now having trouble getting pain meds. (No matter how you feel about the opioid epidemic, most patients that are prescribed pain meds desperately need them to get through the day. They rarely abuse them and don't get "high" from them, they just get pain relief).

There's a two-day window for refilling these C II drugs. You can only fill them two days before you run out. If your insurance is contracted with the company that makes brand-name Adderall, they won't pay for the generic without a prior authorization. This means we email the doctor, along with every other pharmacy and request that they complete the PA process, which can take anywhere from three to 10 days if started immediately. By the time we have an approval, we may not be able to get a brand name or have run out of generic. We get about 50 calls a day from people looking for a specific drug that's in short supply.

Sometimes we only have a small amount, and run out before they're able to get ahold of the doctor and get a prescription to us, and they have to start again. These types of meds are non-transferable. The doctor has to cancel the Rx at one pharmacy and send a new one to the pharmacy that has it in stock. We also have insurance companies that call us to find out if we have any of these drugs in stock, and base their decision of whether to pay for a brand name on the local results. I recently had an elderly patient that is wheelchair bound and had been without pain meds for a week. We had 20 mg tabs that she could cut in half for her 10 mg dose. Insurance wouldn't pay for that.

They had called and found some 10 mg tabs at another chain 5 miles and two bus transfers away and based their decision on that. If she could stand the pain until she got there, and if the doctor could get a new Rx to that pharmacy before the other 50 people in town that were out of that drug got there first and they ran out. Or if, she got all that done in time, spent half a day in agony to get there and found out through a sign on the door that the pharmacy was closed for the weekend for lack of staffing.

If a patient is on Medicaid, and has a tele-health appointment, or is in college with their primary doctor in another state, Medicaid will not pay for the Rx, because the provider isn't registered with them. This happens with new prescribers in this state who didn't realize that our state Medicaid requires prescribers to register.

If a prescriber writes for a drug that's not on the patient's formulary, it requires a PA. Hospitals and urgent cares don't do PAs. If a prescriber writes for a "form" that's not covered, such as chewable tablets versus regular tablets, it's not covered. Some insurers will only cover capsules of one drug, or tablets of another. Inhalers can run into hundreds of dollars, and almost every insurer has a preferred brand. If the doctor writes it for a non-formulary inhaler, many patients can't afford it, and in order to breathe, they can't afford to wait.

If a patient responds to treatment better by taking a lower dose more often, the insurance may refuse to pay and require a PA or a higher dose taken once daily. If the patient has a hard time remembering to take their evening pills, the doctor may prescribe a long acting once-a-day dose, also requiring a PA depending on what drug it is. If a patient just had surgery and needs a pain med for the first time, the insurance will label them "opioid naive" and limit them to a seven-day supply, even though the surgeon gave them enough for the two weeks they'll need it. CII meds can't be refilled. The surgeon can't prescribe more, because they only treat the patient once for the surgery.

If they have a follow-up, and if they can get in to see them after a week, they may prescribe more. But they are also paying for another appointment and may not be ambulatory, so they pay out of pocket, or go without. If an insurance company thinks the doctor is prescribing too many pain meds (without knowing what

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surgery they had, or how severe the injury was), they demand a PA. Hospitals don't do PAs, and it takes from three to 10 business days. So again, they pay out of pocket, or do without.

All of these examples are not isolated or rare. They're happening dozens of times daily in just my pharmacy. They're resulting in serious lapses in treatment and patients paying out of pocket or going without. They're impacting those with limited resources or an inability to navigate the health care system due to physical or mental impairment. They're bogging down our health care system and stretching our resources. What gives an insurance company the right to decide which medication or regimen is best for the patients? Most pharmacies aren't even answering their phones, because they lack the staff, or are calling doctor's back for clarification, or permission to switch to tabs or caps, or are on endless holds with insurance companies. Most patients are going without other needs to pay for their meds out of pocket, if they can. Please help us help our patients! I would love to testify in person, but we don't have enough staff for me to take the day off.