

Oregon Drug Price Transparency Program – 2022 annual report exhibit

Exhibit: Stories from consumers received by DCBS through Nov. 29, 2022.

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NOTE 2: The term "donut hole" refers to a coverage gap in Medicare drug plans created by drug plan limitations.

"We have insurance through my husband's work. Most of the time we utilize GoodRx for our prescription drugs because of the cost savings compared to our pharmacy benefits we receive from our insurance. All of our prescriptions have increased in price – anywhere from \$20 per prescription to as much as \$300. The largest increase we experienced was for our daughter's EpiPen. The price was so expensive for an EpiPen that we were unable to refill the prescription. I believe that without government regulations in place to keep medications affordable for middle class, working Americans, the cost of drugs will only continue to rise.

Our future will be where most medications will be unaffordable for the majority of Americans. Those of us that are working and contributing to society should be able to afford medication treatment prescribed by their doctor without having to choose between food, paying rent, etc. or their medications."

"Insulin costs hundreds of dollars. Type one diabetic for 37 years, trying to take insulin to save my life!! Yet Narcan is free. Do you see a problem with this?

Ampyra costs hundreds of dollars. I have had multiple sclerosis for 26 years. I fall multiple times per day. Ampyra reduces my risk of falling, drastically. Affording the med is not easy to come by. Right now, for example, I have none. So, I do not move to not fall. Yet Methadone is free. Do you see a problem with this?

Methylphenidate is listed as a CONTROLLED substance, yet without it I am asleep all day! So, each morning I have to ask myself: Am I awake so I can walk for exercise and to control my blood sugar numbers or am I asleep all day?

The answer is simple to me, but I am biased because I want to live!!"

"Adderall XR is extremely hard to get insurance to cover. Not covered (it) was \$300 per month for my 30-day supply. Then insurance wouldn't cover the dosage prescribed to me. I got tired of fighting to get it, so I told my doctor I was done taking it."

"I have to carry an EpiPen with me as I am allergic to bees. My insurance will not cover the cost at \$750.00 and I can't afford that price. What I finally did was get an Rx prescription for epinephrine and three syringes, all for under \$40.00. So, the med is high but that pen, at more than \$700, is way out of line!"

"My concern (complaint) is with the initial price for a drug named Tibsovo. I have AML and I take it along with chemo. The drug retails for \$37,000/ month!!!

I'm retired and thank God I have insurance, which to this point has been taking care of most of the expense. I'm lucky, some folks don't have insurance and not being able to afford it, to put it bluntly, just die.

How in the world is a drug company allowed to sell its product for that exorbitant amount of money? I know they have no conscience. I know there are usury laws for interest, why aren't there laws to counteract this kind of raping and pillaging. Greed and a corner on the market. There is no alternate.

I understand R&D costs. I guess maybe they are trying to recoup all these in a year? Some things in life just don't make a lot of sense and this "thing" that doesn't make sense is costing people's lives.

It's a travesty. I'm lucky, although my cancer is terminal, incurable, I'm still pretty mobile. It's a total catch 22. The drug is so, so expensive, but it is part of the regimen that is keeping me alive. But that is the major reason the drug is so outlandishly expensive. Again, pharmaceutical mentality and greed.

I don't mind someone making a buck. Was in business for many years. But this is ridiculous, which really doesn't describe it, but I'm being politically correct."

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"I have spent 8 hours on the phone trying to get my pharmacy to overnight me a med. This morning, when I told the guy at my insurance what was happening, he said he would, do an override and I would get my Rx overnighed to me. I thought everything was solved. When I went to check this had been taken care of, there was no record of it. I went around and around trying to get the Rx that was ready for pickup changed to a shipped to me one.

When I spoke with a representative, I asked the guy, "Do you think I should drag my sick ass around town on the bus, spreading my germs, so I can go pick up the Rx?" He said, "That would be optimal." I think the CDC would disagree.

After many, many attempts to get this fixed, finally my pharmacy is overnighting my Rx to me. At a surcharge of \$19.95 after my insurance already told me they had solved the problem. If it wasn't critical that I have this med, I would wait for the delivery. But I need it now and telling a sick person to take public transit while ill is not the solution I was willing to accept. You would think that after 8 hours of trying to get this right, they would waive the charge as a courtesy.

Not only is my time not valuable to them, I have to pay for them to make things right. I am on Social Security disability and the money they are taking from me would have been spent on laundry or shampoo. The other option is to put my health at risk and not take the med. So, both my insurance and my pharmacy are acting badly here."

"The United States has the highest drug prices in the world. Our politicians refuse to address the problem, instead they implement laws to prevent negotiating drug prices with Big Pharma. Another problem on drug prices is the control the PBMs have on determining what we pay for prescriptions. Three major PBMs are the biggest PBMs and some are owned by big chain pharmacies. Insurance companies are creating another problem by contracting with certain pharmacy chains as preferred pharmacy for you to obtain your prescriptions and if you do not use there system, you end up paying a higher price for your medications.

In 1996 I semi-retired because I got tired of battling Big Pharma and insurance companies on what I paid for drugs and what I got reimbursed from the insurance companies for the prescriptions I dispensed. Had a chance to travel around the world. I visited pharmacies in every country that we were in and talked to pharmacist. When in Greece I purchased Voltaren Gel which was still on prescription with a whole sale price of over one hundred in the U.S., but I paid five euros for the same item without a prescription.

Then the manufacturer took Voltaren Gel of prescription and it sells for around twenty dollars. Why was it so high in the first place? Not for profit hospitals and the VA are allowed to negotiate prices with Big Pharma but our Medicare and Medicaid programs are not allowed. During the time I owned my own pharmacy we used to tell or local and federal legislators what was happening in the drug industry. After our visits Big Pharma would come in and tell the legislators that we did not know what we're talking about. We have a big problem and we need help from our government."

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"I am an optometric physician. I am very concerned about drug prices getting out of hand for my patients. I prescribe medication for a variety of ophthalmic illnesses. This includes conjunctivitis, iritis, glaucoma, dry eyes, pink eye, viral conjunctivitis, Herpetic conjunctivitis and other diseases. I prescribe topical eye drops and ointments as well as ointments and oral medications.

There are two glaring discriminatory examples are the non-coverage of medications by insurance companies and the discounts they do offer are only for patients with commercial pharmaceutical benefits.

As an example of non-coverage of a medicine that is not covered is an eye drop that is prescribed for glaucoma. Many times a patient's eye pressure does not respond to a single eye drop medication. An additional one or two medications may be added to the original medication. This means the patient may be putting up to 8 drops of medication in each eye through the day. Think of hard this is for patients to do and remember. Some of the medications sting. Compliance is a very difficult thing to monitor but you can imagine how hard it can be to keep up with the medication. Surgery is a possibility but not always practical.

I will then prescribe a combo medication that has two medications in one bottle. The insurance companies do not look at this as a compliance management solution, but rather an increased cost. They "suggest" I consider using a different bottle for each of medications in the combo medication. We are back to point zero.

Another discriminatory act by the manufacturers consist of having discounts available for the patients with commercial insurance. If the prescribed medication is not covered or the copay is high, the subscriber can go to a manufacturer's website and apply for a discount. These discounts can be substantial. However, those patients with government programs like Medicare, Medicaid and Veterans, cannot seek those discounts. I think it is because the government is not negotiating medication prices with manufacturers, but I do not know for sure. Our seniors and Veterans are the people of Oregon in the most need of lower priced medications.

The congress put together pricing negotiations but it is woefully inadequate to meet the needs of our patients and much of the benefit does not even begin for 1 to 3 years.

I do not know what the state can do to help these issues, but there is no time to waste. California has helped with insulin costs. I know there are other priorities in health care, but I hope I have illustrated at least some of the difficulties health care providers have in getting the best treatment options to our patients."

"I have part D coverage with Medicare and it is obscene to me that Good RX, a free card, has better prices on so many drugs than what I am getting. Also many of the drugs that older folks need even short term are in the top tiers price wise. Why can't drugs be one price from every insurance and drug store???"

"I have degenerative disk disease and have had it for years. After I got on Medicare my opioids were no longer covered due to the States war on opioids. The people like myself are not the ones that are causing problems with prescription medications. We are made to suffer the consequences and aren't able to have any kind of normal lives. Please reduce your restrictions on opioids for seniors! It's greatly needed for us to have a semi normal life."

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"I was diagnosed with rheumatoid arthritis at the age of 27. Over the first year and a half after being diagnosed, I tried all of the "first line" medications under the class of disease modifying anti-rheumatic drugs (DMARDs) - sulfasalazine, methotrexate, leflunomide, etc. After failing out of multiple DMARDs due to toxic and intolerable side effects, I was prescribed Xeljanz, a specialty medication that retails for ~\$4,000 per month. It managed my symptoms without toxic side effects, and I was able to take it for another year and a half without issue and a manageable monthly copay (\$40).

When I switched insurers after getting married, suddenly, I was confronted with an insurance company that did not want to cover this medication (and if it did, wanted a \$70 copay for it). I had been taking this medication for almost two years at this point with almost no issues. I was confronted with the option of paying out of pocket for the medication or missing an indefinite number of doses. The insurance company obscured the reasons for denying coverage, and made it impossible to weed out what they required in order to approve the medication.

I spent hours daily on the phone with the pharmacy, my doctors, and various departments to try to figure out how to appeal the decision and get this medication that prevented the irreparable damage my disease wreaks on my body. I am still in the middle of trying to get my medication covered. I cannot pay \$4,000 out of pocket for a single month's worth of medication. I have now missed several weeks of my medication and my symptoms have returned in spades. I spend many days in pain, unable to work, and stuck on the phone with my insurance company, chasing answers and decisions."

"After trying several inhalers, online 1 works best for me. Unfortunately, even with insurance I have to pay anywhere between \$50 and \$75. That's on top of all other meds I need. I have resorted to not use it as directed, i.e. rationed it....which I suspect contributed to what happened last months when I was admitted to the hospital with acute AFib and water in lungs and by my heart. Of course, now I owe even more money for that adventure...the only "upside" is that I reached my max out of pocket and get my prescriptions at no cost to me until Dec. 31st.

I don't use my expensive prescriptions and avoid medical care because the price tags are enough to give you a heart attack!"

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"I can provide written testimony as I suffer from several comorbidities (psoriatic arthritis, diabetes type II, high blood pressure). I retired on disability through Social Security but my wife still works through a private employer. I'm on her insurance as my primary but I have Medicare A/B.

I was in a program for my psoriatic arthritis for an infusion through Janssen (Simponi Aria). Because I am now on Medicare through my disability I no longer qualify for that program.

Going forward my infusions are going to cost me \$300 an infusion (8 weeks apart). I'm not sure what other charges I may be inline for. My diabetes medications through my private insurance is \$2,000 for a 3-month supply. I'm not sure what we are paying towards that. Another drug I take, Jardiance, is \$400 a month even using a manufacturer coupon. Frankly, I don't take medications and I stretch out my insulin now.

I also haven't signed up for a Medicare supplement because we have a daughter and we need to provide insurance for her, so my wife has us on a family plan through her insurance because that's the cheapest option. We do reach a point as a family where we max out our expenditures. But there is a huge hole in Medicare and my wife will be retiring herself in a couple of years.

Without the psoriatic arthritis medication, I would literally be bedridden and possibly asking my doctor to allow me to end my life under Oregon law. My arthritis is really intolerable from a pain and skin perspective. The treatments are a biologic and very expensive.

Even after treatment, I spend a lot of days in bed. I am in pain 24x7. The point is a lot of the programs that drug companies provide patients are often not available to Medicare patients and the rules that were put in place are ridiculous. I can see a future where I can't afford my medications at all. I will also go on record, I have been pretty much solid middle class all of my life.

I know once my wife retires and we go on Medicare we're not exactly sure what are health care looks like from a cost perspective. Might seem a reasonable sound byte for the work Democrats did to get cost of Medicine down, but even 20% or \$2,000 a year may push us to an edge with staying in our house. We're 60-65 in age. I can't fathom what late 70s to 80s looks like with the rising cost of medical care. Thank you for your hard work."