

## Oregon Drug Price Transparency Program – 2023 annual report exhibit

Exhibit: Stories from consumers received by DCBS through ~~Nov. 30, 2023~~ Dec. 13, 2023.

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"My cat has asthma. His vet prescribed a flovent inhaler. It's the same one used by people, no difference at all ... A Flixotide Evohaler 44 mcg (120 doses) was (with the DISCOUNT) over \$200 at Walgreens. \*every two months\*! That's awful and my cat would have died because I couldn't afford \$1,200 a year for just one of his meds. ... I went online, found a Canadian 'pet meds' line that would work with my vet via fax to verify the scrip, and mail me the exact same item every 2 months for \$41. Yes, that includes shipping from Canada. Same manufacturer. Nothing different at all.

"Then there was the time we lost our health care for my son who has ADHD. The pharmacy was providing his Adderall for our union health care of \$25 for 3 months. I tried to refill it once we lost our insurance ... would have been \$1,300. We didn't have that, not even close. I called everywhere, and found a 'deal' with coupons for his Adderall for only \$675. Wow. I had to borrow from friends to get my son his meds.

"No one is losing money offering our health insurance discounts, and no one is losing money selling me our cat's meds by mail. We are being ripped off by pharmaceutical companies. ... I cannot believe that in the U.S.A. we are using coupons and pharma commercials advertise that if you can't afford them to call and see what they offer to help. This is nuts. This is not a healthy way to manage getting medications to people. Government should know the exact cost of every item and the markup profit price and our privately owned pharma providers should not be raking in record profits off our pain and suffering. Every new drug has input from federal research, federal grant money, and often uses university research. They don't spend their own money to develop any of these drugs, and yet they hide that from you. ...

"Cap prices, demand transparency, and create an agency where consumers can call and get direct help to find their meds at a reasonable cost or have our gov pick up the balance on their meds. Correlate the pharmacy prices state by state. Collect URLs of where to get discount meds. \*\*Approve mail order from Canada\*\* on everything and let the pharma industry know we aren't going to turn in coupons for heart meds, diabetes injections, cancer treatments, or anything else. That's demeaning, dehumanizing, and disgusting."

"We are a low-income family on OHP Medicaid. My 28-year-old has multiple chronic illnesses, so I also buy an ACA Obamacare plan so our long-term Kaiser psychiatrist can continue providing care. The OHP Kaiser plan did not cover psychiatry. The OHP mental health is weak with long, long wait times and we'd start way back 10 years ago with diagnosis, etc. In spite of these 2 plans, we struggle with prescription costs. I had to come up with \$426 last month, although I am on Social Security retirement and work as a low paid caregiver. This covered a monthly dose of a self-injected antibody that has given my 28-year-old huge relief from daily migraines, Postural Orthostatic Tachycardia Syndrome (POTS), and depression; the medicine is Ajovy.

"Kaiser refuses to do the injection, although they diagnosed anxiety and know the injections cause anxiety. Last month my 28-year-old was ill, but the injection was overdue, and they began having the severe migraines, so they tried the autoinjector and spilled the medicine. Kaiser refused to replace it. OHP refused also, saying Kaiser needed to bill them on the Open Plan Card, which Kaiser refused to do. I had to work extra hours, incurring back pain, and now worry we are over the Medicaid income limits. It is a catch-22 situation. Please help us. Thank you!"

"This effort is the largest waste of time for the State of Oregon. It does absolutely nothing to improve prices or healthcare outcomes. It is typical feel good State government with zero action or substance. Please defund this effort and put the money back into taxpayer pockets. Stop wasting our money."

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"Thyroid medicine that is not a "new drug" is \$200 a month if discounts are not available. I have to take this one, none of the cheaper ones work."

"I have been taking generic Propranolol capsules once per day for many years. Until this year the prescription was a covered benefit with my insurer, and a 90-capsule refill from the online pharmacy, mailed to my home, costs approximately \$37.87, of which I paid co-insurance of \$16.00 until I reach my out-of-pocket maximum.

"I turned 65 in September and enrolled in a Medicare Part D plan with an insurer. This policy costs \$12.50 per month and has a \$505.00 annual deductible. When I price my next refill, 60 mg capsules, 90 day supply through the insurer website, I am quoted the following comparison prices at different pharmacies: \$144.65; \$126.34; \$126.34; \$126.34; \$135.19.

"It appears that because I am using insurance, the cost of the drug has been inflated by nearly 400%. This pricing is really alarming when you price the drug using the GoodRx, a discount prescription drug program. A 90 day supply of the same capsules, using the GoodRx discount code, will cost the following at some of the same pharmacies: \$32.85; \$45.84; \$28.94; \$22.44.

"That is a dramatic difference in price. If I use the discount card to purchase the drug, the full year of the prescription will cost less than the cost of 1 refill of the prescription with the Medicare Part D insurance. If this is not price gouging, then I do not know what is.

"I would note that the Medicare Part D program I chose is the least expensive available in Oregon. I cannot avoid having Part D without facing a late enrollment penalty later in life when I would otherwise enroll (presumably when I would be sicker and need more prescription drugs).

"There is nothing fair, or reasonable, about the price inflation using the insurance program. It should be unlawful for drug providers and insurance companies to inflate the cost of prescription drugs based on the use of Medicare Part D insurance."

"For 2024, my current Plan D with Cigna increased the annual deduction from \$100.00 to \$145.00, increased monthly premium from \$54.70 to \$65.20, and changed my Eliquis charge from a \$47.00 monthly co-pay to 20 percent of total monthly cost. The current 3 month cost is \$1,797.00. It is like being in the 'donut hole' all year."

"I have to use an inhaler, Symbicort. Inhalers are in Tier 3. I have a Medicare Part D drug plan. There is a \$509 deductible for Tier 3 items. For 2024, that deductible is going up to \$549. Then when the deductible is met, I have Silver Scripts, the cost per inhaler has been about \$71. I have never understood why there is this big deductible for Tier 3 inhalers. I'm already paying for Part D premiums and Part B premiums plus a supplement for Part B. Most of this comes out of my Social Security benefits check each month. Please work on this deductible to drop it. I don't have money for that. I am not the only person with this situation."

"Spiriva Respimat is the drug name. I need 2 puffs a day ... this would cost me \$1,000.00 a month. We tried to get the company that makes it to help me. I make \$17.50 a hour working full time and was told I make too much money. My doctor gave me 2 sites in Canada and wrote me a prescription, so I can obtain this."

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"I had lost my job during COVID, and, of course, medical, dental, and prescription coverages. Found another position, farther from home, which lasted almost 2 years before they closed their doors. Again, lost medical, dental, and prescription coverages.

"I am on 3 maintenance type medications and Walgreens is my pharmacy. On this particular visit, I was only having 2 filled at the time. The cost WITHOUT insurance was going to be over \$600.

"I was scrambling to come up with that amount. When the gal at the pharmacy, who knew me to be in there as a regular customer, suggested I get the GoodRx app, AARP free prescription card (if you are a member), PLUS use their free Walgreens discount prescription program. I quickly obtained all 3 and gave her the information to put in their system. I left there paying \$45 for BOTH prescriptions!!

"I am NOT advocating for any certain pharmacy, or prescription program. I am showing you how much it is OUTRAGEOUS! And if you are unemployed, whether or not you are getting any kind of benefit from unemployment, or even the state level. You can CLEARLY see the HUGE pricing difference!!

"Thank you for your time, and letting my voice be heard."

"I am currently prescribed Vascepa (icosapent ethyl – a high quality fish oil derivative) manufactured by Amarin Pharmaceutical in Ireland. A generic capsule of icosapent ethyl is available from Hakim Pharmaceutical in Ohio, USA. WellCare Prescription Drug Insurance by Health Net will cover the brand name (Vascepa), but not the generic drug. Health Net states that is a formulary matter. CVS Mail Order Pharmacy (located in Illinois) will not fill this prescription with the generic brand, because of the contract with Health Net specifically states that they will not issue the generic form of Vascepa.

"There is a big price difference between Vascepa and the generic icosapent ethyl. I discussed this issue with WellCare/Health Net headquarters. They stated that this matter was a formulary matter, and, though Vascepa is covered, the generic form, icosapent ethyl, is not covered. The staff I talked with would not elaborate any more than that explanation. That is it, a formulary matter!

"CVS Mail Order Pharmacy staff states that unless Health Net changes their instructions to CVS, CVS is unable to provide a generic Vascepa. I do not understand the position that Health Net has taken. And, I thought pharmacies (like CVS) and insurance had to offer generic medications when available. Can you help me with this matter?"

"My husband is on Medicare and the UHC AARP plan and he pays out of pocket \$460 every 3 months for Jardiance and \$400 for Eliquis. These are required to keep him alive per our primary doctor and not due to the ridiculous advertising we're subjected to non-stop while watching TV. We are both on a fixed income and cannot afford this.

"One step we should take as a nation is to ban prescription advertising to the public as is done in most countries except for the US and New Zealand. Only doctors should be made aware of their fabulous drugs.

"These ads must be very costly as they air in prime time and include elaborate casts of actors with dancing and singing. Tell the drug companies to pass the cash savings on to those who really need these drugs. The Jardiance "little pill with the big story to tell" is particularly heinous given its cost to us."

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"I am on fourteen different medications. I spend more than my mortgage every month, and still have to split pills and cut back wherever I can. My so-called insurance company recently denied my Rx for a medication I have taken for nearly 20 years and it is the ONLY medication that has ever worked for me. My doctor appealed twice and they denied it twice. I cannot afford a \$360 co-pay (from Gold Rx), or the over \$1,100 for a thirty day supply without the insurance. I have just literally spent the last two weeks in bed sick. I will not buy the 'suggested' medication because I have already tried it and I know it doesn't work. I can't throw away \$60 for something that I know will not work. This country is inhumane in its so-called 'healthcare system.' I have also now lost two different doctors in the last five years (the first I had seen for thirty years), because they can no longer deal with arguing for hours every day with insurance companies over how they are treating a patient. It should be criminal."

"I have Rheumatoid Arthritis. I was on Methotrexate, but it was destroying my energy level, so I went off and tried a few other medications. It did not work and my Rheumatologist wanted me on a biologic with a co-pay of \$1,800 a month. I could do it, but it would destroy my retirement, and once I'm at the level where I need long-term care, it would wipe me out. How the devil does one financially plan for such huge jumps in financial needs? I am a retired financial advisor, I know the profits drug companies and insurance companies are making. America has failed the people, especially senior citizens."

"Being new to Medicare this last year has been a real eye opener! Previously, while working and having commercial insurance, for the MOST expensive meds (i.e., Humira) you can use the company's \$5 coupon, but not so on Medicare. Even with Part D it is an astronomical cost. Same with Eliquis and many other drugs. We continue to let drug companies dictate and the government joins right in with them."

"I have a severe anaphylactic allergy to bee, wasp, and hornet stings. I am supposed to carry EpiPens during the warm months. I can't afford to do that. The last time I filled the prescription, about 4 years ago, my out-of-pocket cost was \$360 and this was AFTER the insurance paid portion. This is absolutely disgusting profiteering from other people's misfortune."

"I'm 82 years old and I'm taking Trelegy. It keeps me alive and I am able to work part time as a caregiver. The cost of Trelegy is totally out of my price range. I receive Social Security and I have approximately \$350 left to live on after I pay my rent, which is \$1,005 per month.

"I am very fortunate to have my Trelegy medicine paid by another and I am grateful beyond words for their help, but they have a lot of people to help and if they couldn't help me, I don't know what I would do.

"My prayer is for reduced medicine prices for all.

"Most of us have held jobs and raised families for most of our lives. We are grateful to still be here and able to work, but sometimes it is just very difficult.

"If there's anything you can do to help everyone I would be so grateful and I'm certain many others would be grateful also. Thank you for all you do. Holding all of you in prayer."

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"It was not until I entered primary school that I learned just what it meant to be obese in this society. I grew up in the 1970s, a time when seeing a severely obese child was not as common as it is today. My peers in school turned me occupying a bigger body into a target for their fat bias fueled insults. I was devastated by their taunts, as a result, I had issues with self-esteem. My mother, who was also obese, considered putting me on diet pills at the suggestion of her diet doctor. Again, this was the 1970s and these pills were nothing but stimulants, speed. The mentality then was whatever means necessary to be skinny but not necessarily health. Thankfully, my mother didn't put me on the diet pills. None of this was my mother's fault ... she was doing the best she could, for the times. This was before obesity was considered the disease that it is and not a moral failing. Through my adolescent years, my struggle with obesity continued and further affected my health and mental well-being.

"In my 40s, I reached my highest weight ever, 410 lbs. The effects of a lifetime of chronic obesity had taken a toll on me. I had co-morbidities that brought my quality of life and life expectancy to a shallow depth. I could barely walk from my apartment to the mailbox. My primary physician suggested a consultation with a bariatric surgeon. This was the start of reclaiming a life never realized. In 2013, I had sleeve gastrectomy surgery. With the assistance of weight loss surgery and a lot of hard work, I got down to 249 lbs. With obesity being the chronic disease that it is, I still struggled with my body fighting to return to its higher weight set point. This is a real struggle for people with chronic obesity and who have lost weight.

"In 2023, I had to get revision weight loss surgery, due to severe GERD (gastroesophageal reflux disease). My surgeon explained that this surgery was not for weight loss. I could be expected to lose no more than 30 lbs. on average. I started taking Ozempic about 5 months prior to my surgery. I went from 286 lbs. to 245 lbs. being on the medication. The 45 lb. weigh loss improved the arthritis in my knees and brought me closer to meeting the weight requirement in order to be cleared for knee replacement surgery. I stopped taking Ozempic while recovering from surgery, per my surgeon's orders. My weight loss was slow to non-existent with revision surgery, just as predicted. I only started to lose weight again, after restarting Ozempic. Currently, I weigh 175 lbs. and am moving closer to my goal weight of 150 lbs.

"I'm afraid all of my momentum to create positive health gains will cease in 2024, because my insurance company will no longer cover Ozempic for me. After learning about this, I felt like I was set adrift in a small dingy taking on water. I began frantically bailing water to come up with a solution to this problem. I could not afford the \$13,000 out-of-pocket for a 30-day supply. Obesity is a complex chronic disease. Just like diabetes is a chronic disease, more than one type of option may be needed as treatment. Why isn't chronic obesity treated the same? I believe weight bias plays a role in the decision to deny these medications to people experiencing obesity. For individuals such as myself, these new weight loss medications are not prescribed for a vanity purpose. They are a tangible lifeline to improved health, well-being, and hope for tomorrow.

"The solution to this problem is to treat obesity like any other chronic disease. These weight loss drugs should be available to people, as prescribed by their doctors. The high cost for these medications needs to be reined in to make them more affordable for people who need them. The same type of intervention that the President provided for insulin cost might be needed in this instance. Oregon ranks 39th in the states impacted by obesity. This makes the need for expanded access to care even more urgent, and not to be kicked down the road for another day."

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"I take 3 prescriptions for dementia. Two are generic, (the) covered one is a tier 2 medication, which is a little over \$200, and I have a co-pay of \$59. However, I see one advertised for dementia on TV. I looked it up and it is \$2,000. That is obscene. I've been pretty lucky. Do I think this industry is pure greed? YES! However, I am 82 and have dementia. You need someone who is willing to take them on."

"My struggles with obesity began in my teens. It wasn't until I was diagnosed with Polycystic Ovarian Syndrome and Thyroid issues in my early 20s, that I began to understand why no matter what fad diet or crazy exercise routine I tried, I was absolutely unable to lose weight and keep it off. I found myself in my mid-30s, three small children, and sicker than I have ever been in my life. I filled 14 medications at the pharmacy every month for comorbidities of obesity, but nothing actually worked to treat my obesity.

"Finally, in 2014, I had bariatric surgery and it was the best decision I have ever made for my health. Even though I was able to lose 100 pounds and move from a 'morbidly obese' body mass index (BMI) to a 'normal' BMI, I still struggled to keep weight off, even when I was still maintaining all of my healthy lifestyle choices after surgery. It wasn't until my doctor added FDA approved anti-obesity medications to my treatment regime that I finally felt relief from the constant hunger and food obsession that I felt, even after surgery. I have faced many hurdles in my obesity journey, and, because obesity is a lifelong chronic disease, I will continue to battle this disease every single day of my life no matter what the number on the scale says. This is why having a chronic disease is so hard on patients – it is physically, mentally, and emotionally draining to never get to take a break from worrying about every bite of food you put in your mouth. I have needed, and will continue to need, access to all of the tools in the obesity treatment toolbox, including but not limited to nutritionist, physical therapist, mental health care provider, FDA-approved anti-obesity medications (AOMs), bariatric surgery, obesity support groups, etc.

"The company I worked for had coverage of AOMs for their employees because they were the manufacturers of one of the AOMs. Once I lost my job, AOMs have never been covered by any of my employers or insurers since. Out of pocket costs are \$1,500 and are completely unaffordable for me. This means I am unable to afford and utilize any of the FDA-approved medications for obesity at the available obesity doses. This has negatively impacted my weight management journey as my weight has continued to climb, and I am no longer able to maintain my healthy body weight or normal BMI. This also means that my other medication costs have continued to increase as I have had to add additional medications to treat comorbidities of obesity.

"AOMs have vastly improved my quality of life and are absolutely necessary for me to maintain a healthy body weight and BMI, yet I am unable to access them at an affordable price. People with other chronic diseases (diabetes, heart disease, high blood pressure) are able to access their medications because they are covered by insurance and available at affordable copays. They are not paying thousands of dollars out of pocket for their drugs like patients with obesity are – IF they can afford it, which 98% of us cannot.

"The purpose of health care is to improve health and quality of life, not to save money or make a profit. Cost and coverage issues are keeping new, safe, and effective life-saving treatments away from people who need them most. Anti-obesity medications should be affordable and covered just like any other medication for a serious chronic disease. Individuals should have access to at least the same level of discounts that pharmacy benefit managers and health insurance plans receive. Drug manufacturers should offer long-term patient assistance programs to reduce out-of-pocket costs, like they do for other chronic disease states. Obesity care should be equitable. Not covering proven treatments for people with obesity is discriminatory and rooted in weight bias and stigma. I am here to fight for equal access to affordable medications for myself and others with the chronic disease of obesity."

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"You need Congress to ban ALL DRUG ADVERTISING period. Not even aspirin. There are no drug advertisements in Europe. Drug prices are much cheaper. This would save millions and stop abuse of drugs and let the professionals prescribe the drugs needed.

"You have the big bad wolf cartoon selling drugs. Remember how Joe Camel was selling cigarettes to children. Nothing different there. Expose all elected public servants that take money from drug companies. There's no reason.

"Pharma advertisers in the United States spent around \$1.1 billion in advertising in January 2023. Want to cut costs????

"The United States and New Zealand are the only developed countries that permit direct-to-consumer advertising for prescription drugs. The American Medical Association (physicians) notes that direct-to-consumer advertising inflates demand for new and more expensive drugs, even when such drugs may not be appropriate (November 2015). Want to cut costs???

"Research by Kantar Media tracks drug advertising by pharmaceutical companies 'Big Pharma.' It's big business at nearly \$6.9 billion in 2021 ad spending direct-to-consumers. Want to cut costs???

"In 2021, overall pharmaceutical expenditures in the U.S. grew 7.7% compared to 2020, for a total of \$576.9 billion. Utilization (a 4.8% increase), price (a 1.9% increase), and new drugs (a 1.1% increase) drove this increase. Want to cut costs???

"For 2022, we expect overall prescription drug spending to rise by 4% to 6%, whereas in clinics and hospitals we anticipate increases of 7% to 9%, and 3% to 5%, respectively, compared to 2021. Want to cut costs???

"STOP ALL DRUG ADVERTISING."

"My biggest issue with the cost of prescriptions is insurance companies. Basically, you enter into a contract with a health insurance company and they cover your prescriptions according to that contract. Then part way through the year, they are allowed to quit covering your prescriptions, because they don't like the cost. There is no other contract in the world that allows changes like that midway through the contract. Insurance companies should not be allowed to change what they cover until the next contract year."

"My asthma inhaler used to cost about \$800 per year. This year, the price went up to \$6,000 per year. I wasn't notified that this was happening. It was quite a shock."

"This is just one of 3 inhalers I use, in addition to my prescriptions for other problems. My total Rx bill for 2023 would have been around \$8,000."

"I got the cost down by buying from a Canadian pharmacy online. They seamlessly obtain the inhaler from the UK and ship it for slightly less than I used to pay, about \$760 per year. They also provide far better customer service than my insurer, Aetna."

"If they can do this, why can't we?"

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"As an independent pharmacy owner, the cost of prescriptions is always a concern. However, most new or newer brand name medications are only used sparingly or at a specialty pharmacy. My community in Portland rarely uses these high-cost brand medications and/or find other low cost generic therapeutically acceptable alternatives.

The problem therein lies the ultra-low reimbursement for these generic therapeutically acceptable alternatives. For example, a large majority of generic medications are reimbursed via MAC (Maximum Allowable Cost), which is terribly underpaid claims (around \$1.00 per prescription). Pharmacies are unable to survive, let alone thrive, in such an environment.

Most of my patients are more than willing to pay a reasonable monetary portion for prescriptions (\$10 per prescription per month or \$30 per prescription for 90 days). It is shameful that PBMs would state there would be a rate increase for their patients if there was a change. PBMs basically make the patient pay the \$10 or \$30 per prescription and pay the pharmacy nothing, leaving the PBM off the hook for any payment. Also, this whole idea of "zero" copays has got to go. These are marketing strategies used and funded by the lack of payment to retail pharmacies.

Also, the patient's experience at a large retail pharmacy is abysmal at best. Patients deserve quality care and reimbursement is the main driver of this issue."