Oregon Drug Price Transparency Program

Exhibit 2: Stories from consumers received by DCBS through Dec. 7, 2021.
NOTE 1: There is light editing for readability and length. Names of consumers, family members, and private businesses were removed, except for drug manufacturers.
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I have heart issues and recently had a triple bypass. Many of the best and most helpful medications for heart and other life-dependent issues are insanely high in cost ... $100, $300, $500, per each 30-day prescription - PER MONTH; and that's only the tip of the iceberg! I have had to refuse 2 very critical prescriptions that would have been perfect for me ... $1,000 and $1,200 PER MONTH! PLEASE help hundreds/thousands of us who need these medications to stay productive and ALIVE!

In 1995 the copayment for a month of brand name medication was $30.00. In 2021 the brand medication is not on the insurance formulary and the out of pocket cost is over $1,000.00 for a month. The insurance no longer covers expensive brand medication. I've been informed that if I want a brand name medication that isn't on the formulary I have to pay out of pocket at drug company's cost.

Some drug companies in other countries that manufacture medications have been in violation of unsanitary conditions in warehouses where generic drugs are manufactured and shipped to the USA. In one instance bat droppings and dead rats were found when inspected. At what cost is this acceptable?

I purchase Medicare and a supplemental plan, as well as a part D prescription program.
I take about a dozen prescription drugs. All have copayments until I hit an out of pocket maximum each year. Two insulin prescriptions, one eye drop prescription, one immunosuppressant, and one hormone medication each have a monthly copayment of $250. The other seven medications range from $5 to $249 each month.

I am at the point where I am going to have to take out a loan on my mortgage to meet the yearly out of pocket maximum.
In comparison, my mortgage is $525 each month. Natural gas is usually around $80 a month, electricity usually $60 a month, water/sewer $60 a month, and phone/internet $85 a month.

A few years ago I had to "choose" which medications I could stop taking so it would be more affordable. I can't give any more up.

I order Spiriva, a bronchodilator, from a Canadian pharmacy because the cost in the U.S. is prohibitive. The costs of several other prescription medications that I take have risen, even with insurance. I don't have to choose between food and my prescriptions, but many do. Please do something about this.

I have 4 school-aged children. My husband and I work full time and make too much to be covered by OHP. Being self-employed contractors, we do not have health care through our jobs. We want to be able to afford a decent place for our family and provide the basics needed to keep them healthy and growing. I have type 1 diabetes as well as asthma. The cost of my insulin and my inhalers are so cost prohibitive that I sometime have to skip doses and/or not buy my inhaler.

At some point, these drug prices are going to lead me to a life threatening emergency (which I can ill afford to have), or worse, my children will be without their mother. I am not looking for a hand out. I am not and never have been on government assistance. I want to live! I want my children to grow up strong and healthy! Please help me and my family. I know that I am not alone in this dilemma. Do what is in your power to fix this, so regular people, like me and my family, do not have to make life and death choices every month?

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Living with type 1 diabetes for over 25 years, there were times when I was denied health insurance and Medicaid because my condition was not considered a disability. I lived without health insurance for 2 years and lacked access to affordable insulin (I received monthly samples from my endocrinologist) that led to poor blood glucose control and ultimately vision loss in both eyes. Even today under Medicaid coverage, I am still at the mercy of high prescription drug prices because medications deemed medically necessary by my endocrinologist are not under the drug formularies negotiated by pharmacy benefit managers with pharmaceutical companies. Appropriate treatment for my type 1 diabetes and thus, my fate are in the hands of such economic decisions and lead to disillusionment in the trust in the medical establishment. Advocacy for my well-being should never ever be restricted to what medications that my endocrinologist can receive approval due to price. Having access to affordable medications allows people to look forward to living their lives without the worry and anxiety that internalizes this stress and thus leads to physical manifestations of health complications. Current prescription drug prices are an amalgamation of the intertwined and complicated relationship of how we view and treat health in this country. As Gandhi once said, "It is health which is real wealth, and not pieces of gold and silver." Our inability to rein in the exorbitant prices of life-extending medications means that "gold and silver" are being prioritized and valued more than the viability and salutary benefits for our community's health.Only through holding pharmaceutical companies accountable and responsible for keeping drug prices affordable, will the vicious cycle of health inequities and poorer outcomes be stopped and transformed to economically and politically empower our most vulnerable and afflicted communities.

I went to renew the prescriptions for my inhalers (have been on the market for over a decade - they have generics), because I was having an asthma flare-up. I was told they were charging nearly $2K for a 3-month supply. The last time I refilled it was $155! Now $1,800. I can't afford that. So now I gasp for breath like a guppy out of water.

I am a contract worker for the U.S. government. I spend eight hours per day looking through a microscope. Two years ago I was diagnosed with glaucoma. My doctor prescribed Travatan Z. It works very well and has a generic of Travoprost. I have excellent insurance and my prescription costs is $110 per month. Imagine what the price would be without insurance. This is not a medication I can go without. Being able to see is very important to the average person. Losing my eyesight would mean the loss of my job.

I am able to manage the cost of my medications thru careful planning, but the most costly one - Eliquis - keeps going up. It keeps me from having a stroke or a major heart attack. Others who I know struggle more than me, but it should not be a choice between who survives or not with a simple oral medication.

If narcotics can be dispensed to addicts, then anticoagulants can be dispensed to people caught in this inflationary drug cycle!
Thanks for your time!

My husband uses 5-FU episodically for precancerous skin lesions. A tube used to cost under $10. Most recently the price was close to $1,000. Why??? This makes no sense at all. The medication prevents painful cryotherapy and prevents the lesions from progressing to skin cancer.

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With insurance companies being charged more by greedy drug stores, senior citizen end up in a "donut hole" half way through the year, instead of 3/4 to 7/8 of yearly total, and gaining rapidly. The "donut hole" category is met by me in June this year. This is a financial burden of extra costs having to be met in order to live my life.Years ago, my mother-in-law retired on a fixed income and could not afford her prescriptions. Therefore, she took them once in a while, every other day to stretch, or not at all because of the expense. Too proud to ask for help. Her family did not realize she would do something like this until she was hospitalized with a heart attack. They had 12 hours with her until she died.One of my prescriptions cost me $5.00 each pill, last year. This was MY cost. Do you know the huge hole in my finances I had, until I refused to purchase the pill ever again? You have to investigate the drug manufacturers and get them to reduce the cost. Medicare has to be in charge of drug prescription costs. Senior citizens on fixed incomes cannot afford to live. It's just a choice senior citizen's have to make each month, is it going to be dog or cat food cans on sale that we buy to mix in with our vegetables to make our money last to afford our prescription drugs to live!

I pay $160 for ONE maintenance asthma's inhaler. It lasts 6 weeks, because I use it at half the prescribed dose, so I don't have to buy it so often.

I keep getting prescribed medications that my insurance WILL NOT COVER. It amounts to hundreds of dollars a month. I live on Social Security, and so-called OBAMACARE is a joke. To quote someone I saw on the internet: "Obamacare--it only works when you don't."

Investors should NOT come before the people who suffer, so that they can wallow in more riches than they could possibly need.

My husband and I must continue on retiree coverage, because of the exorbitant amount charged for insulin. Retiree coverage is $950 per month; however, even switching to a Medicare Advantage Plan would cost twice as much after paying for prescriptions! There are so many drugs that need to be reduced.

After 20 years of trying multiple pills to lower cholesterol, which brought on severe joint pain and didn't work - lowering nothing. Now I jump through administrative hoops to get Repatha approved. Meanwhile, they never told me there are other resources, like grants, I can apply for while they're thinking about approving it.

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Is my story going to make a difference?? Here we go for fun!!I am 100% disabled due to chemical exposure. To save time, here is my trickle down effect from working in the extraction of fossil fuels! We drilled for natural gas. I had an exposure related seizure on the drill rig with temporary paralysis. I went through months of testing. It started as unknown demyelinating disorder. When I filed for SSDI, the neurologist discussed my polyneuropathy, but then found MGUS [monoclonal gammopathy of undetermined significance]. Then 2 months later found hypogonadism and the adrenal insufficiency came next. Nerve damage was causing me severe pain. Swollen lymph nodes as well as muscle spasms were so severe that I was punching walls in my sleep and pulling muscles!! I also had severe migraines and eye pain. Later I was diagnosed with Addison's disease. I went from making good money to 100% disabled overnight from an on-the-job injury. I lost my workers comp claim to the crooked fossil fuel industry and paid off kangaroo courts in Wyoming! I pay $300 a month for my Medicare Advantage and another $300 a month for prescription drugs. This doesn't even count the vitamins that I need, therapy co-pays, and specialist co-pays. My MGUS has advanced to stage 1 Multiple Myeloma. I have quarterly testing and annual marrow testing. I have also been diagnosed with white matter disease as of late 2019. I just turned 50 years old this October and have been fighting this since 2013. This is obviously chemical related as benzene is a major problem in fossil fuel extraction and we weren't given proper PPE!!I am having a tough time making it, except thanks to my mother!!

Due to wearing a mask because of COVID-19, I ended up with skin that felt like it was on fire. Very red & painful. My dermatologist prescribed an ointment - almost $400. It didn't help. He prescribed another - $700! Helped a little, but I couldn't pay for a refill of the prescription.

My 12-year-old son has chronic asthma. His pulmonologist recently changed his treatment plan and sent his new prescriptions to the online pharmacy for our insurance. Then they, with no communication or confirmation from us, filled the two prescriptions and sent them to us, along with a bill for $150. They insisted that the receipt of the prescription from the doctor amounted to consent from us to receive and pay for the medicine. One of the medicines we already had plenty of (so no need to pay $100 for a new inhaler), and the other they incorrectly interpreted at a higher quantity. The correct quantity would have cost $10; they sent us $50 worth. It's a "just in case of emergency" medicine, too, so it's not something we will likely use very often. They stood firmly by their "no refunds" policy.

Finally, after multiple calls and emails (including ~3 hours on hold), as well as to my insurance company, they approved a refund for most of the expense (although we're still stuck with more medicine than we need). I was fortunate that I had the time to push back on this; I'm sure this sort of thing happens to folks all the time and they get stuck with the bill. Why is the healthcare cost structure so broken in this country?

When the local store closed its pharmacy, people were forced to "shop" for a new pharmacy. An elderly gentleman I know went to another pharmacy to get a price on a refill for an active prescription from the closing pharmacy. The pharmacist refused to give him a price. He said he needed to have an order from a physician first. This was an active prescription at another pharmacy with refills available! This seems wrong and possibly illegal. Seniors in particular need to get the best prices on their prescriptions. Can a pharmacy refuse to quote a price on a prescription?

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I am on four prescription drugs for chronic conditions. Two of them are brand-name, because they are the only ones that work for me. Costs continue to rise, well above the rate of inflation. One prescription that used to cost around $400/month a few years ago, now costs $778/month.

At one point in time, our health insurance copay actually exceeded the cost of the prescription drug. Had we not specifically asked the pharmacist about other discount options being applied to the $30 co-pay (discount program can be cheaper), we would have been charged MORE than the cost of the prescription without health insurance! My spouse transitioned jobs this year, but unfortunately we did not realize the new job would have very poor health insurance coverage. We now have less expendable funds, even though the job pays a few dollars an hour MORE than the previous job. This is because our share of the health insurance premiums is more at the new job and the coverage is less, resulting in higher copays for prescriptions and medical appointments.

Another family member was unable to afford his insulin medication for his life saving insulin pump. He should be taking a long acting and a short acting insulin medication. He has a good paying job and decent medical insurance. He was also under his mother's health insurance that helped cover his prescription costs until aging out of that option. When he aged out from under his mother's plan, he quickly found out that his "good" health insurance did not cover the medication he desperately needs. He spent his savings trying to keep the medication until the day came that he could no longer afford it. Fortunately, he shared this with me and I was able to tell him about this inexpensive insulin option that a store sells.

Unfortunately, this medication is subpar compared to what he is prescribed. While this option has saved his life (diabetes is very hard on him), it also almost cost him his life while adjusting to it. One night his partner awoke in the middle of the night and he was slipping/had slipped into a diabetic coma. Eyes wide open, unable to move, unable to speak, unable to think, but looking terrified. She was instructed to give him CPR and slip the diabetic sugar supplements into his cheeks until paramedics arrived. Had she not been with him, we may have found him dead. All due to the prescription he needs being too expensive WITH full coverage health insurance.

This is the most impactful story but while adjusting to this change of medication due to cost there were quite a few different situations that arose. One night at dinner he started acting drunk. Everyone was very confused because there was no alcohol in the house. He started out completely normal, but soon was laughing hysterically, falling off of his chair and just being weird. Eventually he started talking about sugars and we realized what was happening. As we attempted to convince him to intake some sugary options such as a Mountain Dew, ice cream, whatever we had on hand, he took off. He is over 6 feet tall and there is not much you can force him to do if he does not want to. Diabetics usually have very sensitive feet and he ran out of the house, barefoot, in the rain, and went up another road. Had there been a car he would have been hit! We were able to get him home and get him to chug a 2 liter of Mountain Dew, most of which stayed in him (although he did pretend to be a fountain with some of it). A few min later he started to "come to" and took his blood sugar. He was in the low 30's. Your level should not be below 70, with anything below 54 being EXTREMELY concerning, and it was a miracle he was up and moving. It is barely below this that the coma starts to set in.

As on of millions of Americans who are AFib I spend $4,800+ per year on blood thinners.

I am on Social Security only and I can't afford a $2,600 monthly co-pay. I filed for medical financial aid and got it for one year, but at this cost, I'm going to need financial aid for the rest of my life.

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Left my local store when they suddenly sold their pharmacy business. Another pharmacy took over all the customer records and prescriptions. They have made no attempt to match the prices we used to get at the old pharmacy. Even using a discount program, they are not offering the prices the discount program website says they will. I'm sure they have excuses for their pricing practices, but to the public, it looks like price gouging.
My husband was diagnosed with aggressive MS in 2019. His neurologist hit a bullseye and the first medication she prescribed was working wonders for him, although it was expensive ($8,500/month). Last year, our insurance company suddenly decided he needed to fail TWO other drugs before they would pay for the medication he needs. They gave him three choices -- all of which were older, injectable medications. His neurologist is concerned that switching to one of these medications will cause a deterioration in his symptoms, and he will never regain that function once he loses it. The kicker is that potentially losing his mobility would only save the insurance company $600/month. We are stuck. We can't afford $8,500/month for the medication he needs, so we are receiving patient assistance from the pharmaceutical company for now. However, they have warned us that our time in the program is limited because we have commercial insurance, even though they refuse to pay.
My hormone drug price just doubled. It was without warning or notification from my insurance agency. This is a patch medication that must be placed every week. They are uncomfortable and bulky and feel like a huge sticky itchy Band-Aid. I used to be able to get another brand, which the pharmacist called a special order, that was much smaller and indiscrete. Now all I do is itch through my clothes that I pay 2x as much for. Yet Viagra is a cheap drug for men that are a dime a dozen. The double standard is gross and beyond understanding.
They are to expensive and not covered under Medicare.
A good friend of mine had recently been diagnosed with type 2 narcolepsy. It was unsafe for her to do basic activities, including driving. Her insurance company at the time, continuously denied her the proper medication, despite having the support of her psychiatrist and PCP as well as an approved prior authorization. Her only option was to either go unmedicated or pay out of pocket, and this specific drug had no generic available. She endured a months long battle with the insurance to gain coverage for her medication and eventually won after continuously escalating, calling and harassing them. Even after the drug was determined to be coverable, because she was prescribed a brand name medication rather than a generic, she had to pay a $500 fee EACH MONTH when she refilled her prescription, on top of any unmet portion of her deductible (which was near $3,000 per family member) or applicable coinsurance. This $500 did not accumulate towards her deductible or out of pocket maximum. If she didn't have the health insurance literacy or time to fight it, she would have paid over $6,000 in one year alone. She could have suffered a narcolepsy attack and fallen asleep while driving. It's absolutely insane that people aren't setting insurance company headquarters on fire.

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I had an allergic reaction to an asthma inhaler. My doctor prescribed a different inhaler. It was not formulary so they sent me to an independent pharmacy. One inhaler with 60 puffs was $1,000. I had to go without.

They set me up with a nebulizer, which did not help. I needed the steroid to open my lungs. I ended up on oral steroids which is horrible for your body and made me even more sick!

It has to stop!

Several years ago I paid for 2 EpiPens because I was forced to buy 2, when I really only needed 1. The cost was 4 times higher then the cost of one EpiPen the year before. So ridiculous. Then I found out after the fact that they didn't even work. There is a class action suit, but that is not much of a penalty for the drug company. Can't the state get involved in these issues? I no longer buy them due to rising cost and the fact that who knows if they even work.

I had worked in the pharmaceutical industry for several decades, working in the government pricing area, and I feel I've seen it all, or at least I think I've seen enough for a lifetime. Pharma is a for-profit business, and we must remember this as we view changes in this market. I understand the argument of how many molecules do not make it to market, and the costs of these lost drug candidates need to be absorbed. Each area of government adds layers and layers of complexity of rules and reporting, which, although it has helped me be employed for almost 30 years in this industry, has not solved the problem of prices to the patient.

As I watch the costs of the prescriptions within my medicine cabinet increase, I am left to wonder how I'd be able to afford these medicines if I did not have insurance. And even some of the suggested drugs from my physicians are not covered, and after seeing the astronomical price tag, I am left to forgo the best option and move toward something else. It also leads me to ask if there are other alternatives or are these medicines necessary for the benefit they provide. Prices are still increasing. The awareness of state drug price transparency has slowed down triple-digit rate increases, but it has not reduced the costs of the drugs to the patients in the states.

I'd like to see the states collaborate and consolidate to increase their purchasing power. In a similar to what the VA and DoD have in the past. This collaboration should be viewed as state-by-state unity for the people. Then in a similar process as other government programs, hold government procurement contracts that are negotiated and capped at CPI-U. Manufacturers of higher utilized drugs would be required to bid for access to the population if they want to do business in the US. This model could add Medicaid, PHS, and Medicare patients to the mix to understand the US population's needs and control costs. Would this alternative be perfect? No - and I'm sure there would be arguments on both sides of the fence. But it's a step to help American's afford the best care.

Prices for our medications are all on the rise. Some have got totally out of hand and all have gone up. With the number of them that my wife and I are on, it is a burden especially on our reduced income.

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I'm on weight loss meds that insurance won't cover ($100 a month). Also thyroid meds (Armour/NP at $35 a month) that insurance has stopped covering (and no idea why, they did until this year). I just started a topical cream for rosacea ($50, no idea how long it will last). We can afford our meds, it just seems odd that the doctor's prescribe meds to help with medical conditions (effective meds too!) and insurance doesn't cover.
My Medicare Advantage Plan informs me that my immunosuppressant meds is changing formulary tiers again. I received their letter Nov. 12, 2021. There was no email even though I have requested this. I have been taking the same generic immunosuppressant since May 2014. I was taking this drug when I first enrolled in my Medicare Advantage Plan over seven years ago. My drug has always been in the formulary but there were several years when the tier was changed to a higher tier. I learned of a "tier exception" after reading through the company's small print manual the first time this happened.How can an insurance company justify referring to a generic as a brand drug and keep changing tiers/cost sharing? There are serious problems in how they communicate plan changes and lack of transparency around tier exceptions. Member and prescriber must keep providing the same information as to why the patient is still taking the same drug and why there are no alternative meds.I am very concerned and stressed knowing they could make another tier change at any time; pushing me into the "donut hole" [coverage gap in Medicare drug plans created by drug plan limitations] - or worse, they could drop it entirely from their covered drug list.
I can't get health insurance and don't qualify for Medicaid. I spend $600 a month just on myself in premiums, and while I am doing my best to regulate my blood sugar, diabetes runs in my family. My father and mother both suffered major medical issues in their 50's, depleting their retirement, it left them bankrupt and finally unable to work. They owe taxes because their medical premiums cost as much as their monthly income, before Medicare finally kicked in. Now the insulin for my father and the anti-seizure medicine for my mother is paid for by me, so they can continue to live in the home they've had for nearly 40 years, refinanced to pay off medical debt.

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This was sent to our congressman today, who insisted any change to how Medicare deals with drug companies be removed from the so called "Build Back Better Bill." It's the easiest way to tells the story. We are truly exhausted by all of this. (Included was a photo of my husband's very bruised arm, a result of having to switch to Warfarin due to the cost of the originally prescribed drug.)Mr. Schrader,My husband retired in July from decades of service to [a state university]. While working, the medications he needs to keep him alive were covered by employer insurance, with minimal cost to us. When choosing post employment insurance coverage, we chose a plan which cost us each almost $400 a month; total out of pocket for insurance is now almost $1,000 a month. We assumed my husband's medications would continue to be covered in the same manner. We got a very nasty surprise to the tune of $195-250 a month each for the two "designer" drugs, another $500 a month in addition to the cost of insurance, because Medicare can't negotiate drug prices nor are its recipients eligible for any of the reduced options offered by the manufacturer. My husband had no choice but to revert to lesser functioning drugs. He now needs to visit a anti-coagulation clinic 2-3 times a week to have the dosage of one of the drugs constantly regulated. The photo below is the most recent result of being forced onto a less effective drug. We are not alone among retirees in Oregon feeling angst about prescription drugs. I am sure your personal gold mine with Big Pharma will prevent you from ever feeling the pain, frustration and fear that we deal with because we can't afford the drugs my husband needs. Shame on you for continuing to support Big Pharma over your constituents. By all accounts you saved them billions of dollars by refusing people like my husband access to reasonably priced drugs. I'm sure they'll show their huge appreciation by continuing to support you. We won't.

Before my husband retired a few years ago, my disease-modifying medications (DMTs) for MS were covered by his group insurance and I paid $100 per month copay. Well, my life changed after Medicare. Even with a good Part D Medicare plan (and a consultant hired by his employer) I had to change my DMT because we would have to pay an amount that would have bankrupted us. We did not qualify for financial aid.

So my neurologist changed medications to one that provided financial aid. That lasted only one year and so I had to change to a lesser-known drug for the next year, 2021, with a new insurance company and co-pay of $295 (not easily affordable but we could manage). During this year my MS symptoms have increased substantially, and I have changed from relapsing-remitting to a progressive form of the disease. I am really furious at not getting the protection I needed for this year because of the medication change and now have to go on a much stronger DMT that will affect my immune system more and make me more susceptible to COVID-19 and other viral and bacterial illnesses.

For next year I have a zero co-pay on my new drug that was arranged by my physician, but I imagine that won't be the case after that. So I've been living in fear about access to my DMTs in the future, at a time I am losing ground with my disease.

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Our eldest son has idiopathic hyper eosinophilia, he was dying without a drug that stopped eosinophils from roaming his body causing significant inflammation throughout. The medication he takes is antibodies against interleukin-5 (IL-5) which the IL-5 would otherwise mobilize the eosinophils and his illness. With the medicine, Nucala, his eosinophil count is low and he has the potential for a normal life, but he takes it every 4 weeks and it costs OHP $9,800 each time. We're on OHP, so his medicine is covered, but we don't know where our future will lead us. There is no way we can pay for this medicine, we don't know if we make enough and can pay for private insurance that we could cover the co-pays - and for now we are voluntarily poor because the previous administration threatened Chip for our kids, knowing that without coverage we risk our son's life. And this kid at some point with either age out of OHP and need to be on his own, but the cost of living is almost insurmountable for him to get a start. We realize we are extremely lucky that there is this medicine that will allow our child to be relatively healthy, but - who can afford to live at those costs? Our future, our son's future, has been opened up, but also occluded by the structure of prescription costs. To me there seems to be no way out, the guilt alone of the cost to the taxpayer is a burden, the guilt that we have a solution for health but not without some hard choices ... I don't know what is right, research gave us this miracle, but the cost now is being borne by everyone - both because OHP covers his costly medicine, but we are not earning an income that would return taxes to Oregon or the federal government.

Our family lives with inheritable chronic diseases - hemophilia and von Willebrand Disease. We have incredibly expensive health care and we pay our way - we are not on government assistance of any kind. Recently, our family was subjected to a co-pay maximizer (similar to an accumulator, but slightly different) and were held hostage by Pharmacy Benefit Managers preventing us from getting access to our medications. The most important point is that we can afford to pay for our medications, but we were still held hostage. Because our story is long and complicated but writing the story will not do it justice - meaning it will be too difficult to understand without the context and detail. I am happy to tell my story in more detail, if needed.

As a physician who cares for people with multiple sclerosis, every week I meet a patient who cycles on and off disease modifying therapy due to job loss, excessive copays, and other logistical problems like having to be home to sign for specialty pharmacy drug delivery and transportation barriers to getting infused therapies. MS has a therapeutic window early in the disease course to prevent or delay disability accumulation. Treatments later in the disease course don't work to slow disability, and there are no effective ways to repair the nervous system. It's not the occasional patient falling through the cracks, but nearly the norm. Healthcare is a patchwork blanket with major holes in it, and drug prices are one of those major holes. Society ends up paying multiple times the cost of medication later due to the costs of being highly disabled- wheelchairs, home modifications, infectious, hospitalizations, and caregiver pay.

I have very bad ulcerative colitis and have to take four Mesalamine pills a day. This prescription is over $1,000 per month out of pocket. If I go through my insurance the cost is still about $750 per month. If I go through a discount program, the cost is $178 per month, but doesn't count towards my out of pocket deductible. All of this, especially when added to other monthly prescriptions, is a great deal of money for my family. How can there be such a big difference in price between my insurance and a discount program? And how can there be such huge differences in price between competing pharmacies?

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I have just received my new "notice of changes" and tier 1 & 2 $$ have gone up. One of my old drugs doubled last year, even though it has been around for years. I am on such a low income that these upticks will be difficult. Having epilepsy, I can not do without these drugs and the doctors visits.We need lower drug prices, not the same or higher.
I'm a primary care physician. I have seen prescription drug prices increasing throughout my career, and in particular have seen patients on fixed income with high deductibles/copays choose inferior medications due to cost. In particular, cost increases in managing diabetes (both insulin as well as newer oral/injectable drugs) and blood thinners for atrial fibrillation are limited in my older patients on Medicare because of cost, despite good evidence that these drugs are both safer and more effective. I frequently find myself prescribing medications that I know are not the best available medications due to cost limitations.
My husband has insurance through work, if we order in the mail we have a $0 copay for a 90-day supply, but if we get it locally, it is a $20 copay for a 30-day supply; obviously we started going through the mail.
Pharmacies are closing over the CAT tax. It is hurting the small family drug stores. With the national chains (that are now trying to buy the small ones), prices will go up and it will be harder to purchase prescription drugs.
Our local pharmacy recently closed. The store noted that they were no longer making money and could not keep their pharmacies open. They stated that there were many causes, a big one apparently being the reimbursements from insurance plans not covering the prices that they need to charge for each prescription. They also noted that they pay things like the Oregon CAT tax, which increases their costs, and makes it more difficult to generate profit. While the State of Oregon can't change the prices that drug companies charge or what the insurance companies choose to reimburse, they might consider not adding fuel to the fire by adding burdensome regulations and additional taxes upon them. Obviously these costs must be passed on to us, the consumers. Alternately, the pharmacy can "eat" the additional costs, but (as we saw with our local store) that only lasts for so long. Please consider reducing Oregon taxation and regulation that drive up our prescription costs.

Oregon Drug Price Transparency Program

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As a retired pharmacist I have visited numerous pharmacies around the world. One example of the highest prices for medications in the world is the US; I was in Greece several years ago before Voltaren was taken off prescription. In Greece it cost 5.95 euros for the same tube that cost over $100 on insurance in the US. Now it is off prescription selling for over $15 over the counter (OTC), but in Mexico the same item is less than $5. I used to provide the snow birds that went to Arizona in the winter the names of medications that they were taking through my pharmacy and the costs were 8 to 10 times less than in the US. They were happy to save lots of money. In the US, the VA and non profit hospitals get bids on their medications, which are again a huge percentage below the cost that a retail pharmacy pays. I have several examples of items that cost me over a hundred dollars per unit, but cost the hospital almost nothing. Our government needs to let Medicaid and Medicare get bids on medication, which would save millions of dollars. We need to get control of Big Pharma, PBMs and insurance companies to bring down the cost of medications. Big Pharma spends more on lobbying and advertising than they spend on research. Our federal legislature is trying to get some control over the high cost of medications and I hope they accomplish their goal.

My wife has asthma. For many years, the purchasing of inhalers (necessary for helping her breathe) have been a financial burden for our family. The health provider would keep changing which brand inhaler it would cover in our plan. The price of each of these brand inhalers varies annually, which we've noticed always goes up in the late spring early summer, coinciding with the Oregon allergy season (pollen, grass). We would pay from $30 to $60 to $170 during peak allergy season for an inhaler that would have 1 month worth of medication. This would be the brand that the doctor prescribed. Many times we would have to ask for the doctor to switch her Rx to another cheaper brand so we could afford it (so it was partially covered by our health plan) and help her breathe. The doctor would usually comply and then we would carry on until the provider would switch which brand it would cover again, then our Rx price would go up again (usually coinciding with allergy season) this has gone on for years (15+) while covered by two insurance plans.

The burden was often great enough that my wife would do without in order to conserve medication and thus $$ for our budget. This practice of manipulating the price of these inhalers to maximize profit when people need the drug most is despicable and flies in the face of what medicine should do; being there to help people. In addition, having to request the doctor to change which medicine to prescribe often meant another visit to the doctor, which also cost us more money. The health insurance scam is rigged so that we often avoid anything to do with going to the doctor because we always get ripped off by manipulated coding of procedures, leaving me to wonder why are we paying for this!!?? Reform the health system to single pay and reform the drug industry to something that works for everyone not just the big companies!!

I take Singulair brand name only and pay $80 for a 3 month supply. The generic form, Montelukast, doesn't work for me. It only costs $14 for a 3 month supply.

The cost of our generic drugs have all doubled or tripled in just the last few years. Yes, for now we can afford them, but we wonder if this steep increase will continue to the point we can no longer pay for all of them.

We copay almost $600 for Xarelto for 90 days. Of course it's worth it because it keeps my husband alive, but again, we wonder what the future brings.

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Myself and my son take the same drug and mine is covered by insurance. Where as, my son is covered by OHP and he gets different prices with each different pharmacy. Some are very expensive and some are just expensive. Why is that?And they keep changing from every 6 months.Thank you.

Two drugs that I use have increased in price just this year:
Metoprolol from $21.78 to $26.00
Tamsulosin from $34.88 to $41.36

I ordered a prescription ointment from my mail order pharmacy and when it came I had been charged $343. I later found out I could have purchased it at my pharmacy for $45 with the discount program card. I have since used the discount program for all prescriptions, but still have to pay my monthly Part D plan premium. What a serious mistake on our government's part to be the only country not to negotiate prices. It is quite obvious who is winning here.

I need to be on Ozempic for my diabetes. I can't afford it due to a cost of $895 per syringe. I'm on Social Security only.

My daughter suffers from a condition that requires a medication that my insurance does not cover. It costs almost $900 a month to get it filled. We have been trying to find it in Canada for her for around $200 per month. I am a public school teacher with good insurance, but it does not cover any prescriptions other than generic. Without her medication she suffers from constant heavy, long, and painful periods due to multiple tumors and cysts. She lives with the pain for now, but it causes her to miss work and school, and ultimately can lead to cancer or the inability to have children. I would happily buy her the medicine she needs if it was at a reasonable cost, but there is no way I can afford it when it costs almost the same as my rent.

Because I am a senior on a tiny fixed income with zero wiggle room (no longer working even though I would LOVE to be still working!), even if I was told I "had to" take a prescription, I would refuse. I would be unable to pay. I am well educated and worked for decades as a paraprofessional in the legal field. I see the relentless politicking surrounding pharmaceuticals and have come to realize that the deliberate obfuscation of the reality of taking medication is just another way for Big Pharma to fill its coffers. The health insurance companies are unholy co-conspirators with Big Pharma specifically to reduce health insurance companies' obligations under - especially - Medicare arrangements to actually pay reasonable percentages for medication. In short: Patients do not matter. Profits do.

My husband has asthma and COPD. Last month alone was $150 for his drugs for this, after insurance paid their part. Our total Social Security income is less than $2,000.

Over the last 5 years, I have seen the prices go lower for the medications that I use and very happy about the stable medical costs we have had over the last 5 years.

As I stated earlier (in questions section), I'm suffering from COPD end stage. I can't even imagine how many overpayments have been paid to the Big Pharma companies over the years because of the lobbyists kickbacks. If I had to guess, in the last five years alone I've paid out over $30,000 in medical costs.

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When I moved to Oregon I was using an over-the-counter inhaler for asthma. The cost at my pharmacy was $12.00 for one atomizer that would last me for 3 or 4 weeks. That lasted for 3 or 4 years. Then one day I went in to buy another atomizer (spray for my lungs) and I was told I need a prescription. So I went to my doctor and got a prescription took it to my pharmacy to get it filled. When I went to pick it up it was $600.00 for one $12.00 atomizer. And that happened overnight. There was no way I could afford that, so I had to do without.My sister has Crohn's disease and was prescribed a drug to control it, the cost $12,000 dollars a month.

As a nurse I see many patients admitted to the hospital for acute exacerbations of chronic disease that could've been managed if the patient had affordable access to medication and healthcare services.

The patients who couldn't care for themselves and get their medication now take up a hospital bed. And believe me, if they can't pay for their meds, they're not the one paying for the costly ER visit and hospitalization. It's the taxpayers. You want to save money on healthcare? Start investing in preventative care. Reduce the cost of drugs so that people can manage their chronic diseases at home. It would also improve these patients' quality of life! But that's not the goal here is it?

My sister-in-law is a diabetic. Her insulin prices are outrageous.
My brother had a heart attack. He has to take a certain medication for a year. It was $15 a month. The price was just raised to $400.

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My child was recently diagnosed with type 1 diabetes. Juvenile diabetes, as it is sometimes called, is an autoimmune disorder. My child is eight years old and is now dependent on insulin for life. To say that our lives have been reset to an entirely new reality would be an understatement. Not only is this diagnosis completely unplanned and unpredictable, but the cost of all the prescriptions to keep them feeling well and alive are, too. Our cost to leave the hospital with the basic supplies we needed to start this journey was around $500, this was after our amazing endocrinology team applied coupons to the drugs we would need. We now average $200 a month out of pocket for test strips, lancets, micro needles, short and long lasting insulin that they need in order to survive. This doesn't include the cost of the sharps containers or disposal fee for the sharps container or alcohol pads, or chewable glucose tabs or any of the other tiny little things that add up, again, for survival. We have private insurance, unfortunately there isn't even one Tier One option for the insulin, needles, or monitoring supplies provided. We were told of this amazing program for Type 1 diabetes that pays for the majority of the supplies, but guess what? We aren't eligible until our child reaches the age of 13. So even though this disease can happen to as young as infancy, we were told we're just out of luck for that option until the golden age of 13 shines on us. So, currently our cost depends on coupons we find online and making sure our doctors prescribe the drugs that are offered in the lowest cost tier plan attached to our insurance plan. For example the fast acting insulin, Novolog, for a 30-day supply we pay about $30, total savings it claims $800(!). The micro needles needed to administer the insulin cost us $50, a savings of $170(!) for needles! Test strips $50, insurance savings $48. Lantus, the long lasting insulin, our cost, $30, after online coupon savings of $100 and insurance savings of $341. This isn't even all the prescriptions! We haven't even been able to consider the option of a continuous monitor, which we were told for a 30-day supply can cost $1,000, or insulin pump or pod system. Both of which would be easier to monitor and have earlier detection abilities if our child was to enter a dangerous and life threatening situation with their blood glucose numbers. I have a hard time finding words to describe how insane this current system feels. Somehow we are living a reality that it is considered a privilege to pay so much for insurance and a privilege to pay so much for prescriptions. A privilege I guess and not a human right to be alive. I can only truly wish and have hope beyond hope that this current system is not the one my child will enter when they reach adulthood. It's beyond shameful that this current system has allowed this to go on this way.

My doctor tells me there IS a difference in the effect on the brain with regards to brand vs generic prescriptions. That's why I notice the difference. However my insurance company won't cover brand name drugs as they've declared brand and generics are exactly the same.

It's also ridiculous that a brand name prescription that cost me $60/month 25 years ago would now cost $1,500/month - IF I could afford it. But I can't, so I'm stuck taking something that doesn't work as well, which makes my work day much harder than it needs to be, and feels so unfair. It's the same medication, that has been around forever. Why such an increase in price??

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My story that I'm willing to share is when my husband was being treated during his third & final bout of cancer. We were both retired, considered middleclass, owned a home built for us after owning homes previously for 28+ years with each purchase improving both in area and quality. We also were grateful we could afford good health coverages for medical, dental & vision care. However, as we got older & health concerns became more serious the costs became increasingly harder to cover. Our insurance was a God send, but the day came when my husband needed a procedure to help him breathe. He was hospitalized & we were waiting to hear what time he would be taken in for the procedure - when we were told he would have to wait one or two days before the specialist could be brought in or pay $29,000 for an available doctor & get it done that day. What would you do if a family member was gasping for each breathe? I had no idea how I would pay for it, but at that moment I would do anything to provide the help needed. That procedure helped & made it possible for him to return home 2 days later with 5 months actively interacting with friends & family; not just laying in bed thinking of his passing. What was just as disappointing as paying $29,000 was the one pill he took the last month of his life - a whooping $5,500! Yes, one pill per week. I used over 60% of the $100,000 life insurance to pay for what wasn't covered by insurance; this is only one of the health issues we were dealing with at that time. Medical issues & being able to maintain care put me in a situation that I no longer own a home, I live on less than $42,000 per year, live check to check, with my primary care provided by an organization that has Nurse Practitioners provide all services (I haven't seen an medical doctor at the group that provides my primary care in well over 3 years) - they bill my health insurance the same for NP services as MD services, so you don't see an MD & they profit 80% more so why care about the patient?! The reason I'm sharing this is because cancer is something that has affected most people in one way or another, so it is a situation most can relate to. I stated earlier in this survey that we were grateful for having insurance. Now I'm in the low income population; unable to work, living on retirement & SSI and being over 70 years old. Medications concern health providers, not that they care about the person, just focused on what is ok to prescribe without have to justify reason. Costs of medications are equal to a trip to the grocery store each month & I shop only sales! I'm not being over zealous about the costs I've personally experienced in my family & friend circle; much of my working life was in the health industry from labs, outpatient services, mental health facilities & the like; I saw the waste & mishandling of medications by non-professionals & professionals. The sad thing is there are people clumped together by their economic groups NOT by who needs medications that would be life changing for them; it's like companies making medications want money & if you're not making enough, then you're not worth it because you don't improve our bottom line.

I need my inhaler everyday for treatment of asthma. I have never smoked or done anything to worsen my asthma. I stay active by hiking and running. I need to use this cortisone inhaler twice a day. Every time I refill it the price is higher. When I started on it in 2014, the price was $80. Now it is over $300 for a 30 day refill. I live off of my Social Security and have high deductible insurance.

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I have an autoimmune disease that causes my entire mouth to erupt into a canker sore. It took a few months to find a drug that worked to clear it up. In that time I went from 130 to 100 pounds. The drug that worked was azathioprine, a drug used for transplant patients. It wasn't too expensive with my insurance. My blood work needed to be monitored every 3 months. After about a year or so, azathioprine caused my white blood cell count to plummet. That was right before COVID-19 started. My doctor prescribed Otezla, a new drug meant for my specific condition. My insurance didn't cover it. The insurance wanted me to try a few other injectable drugs that were not for my condition and probably would not help my condition first - AND had serious side effects. I appealed the decision to my insurance company and it was denied. I then appealed it to a 3rd party through the state. That 3rd party approved me to use Otezla AND the 3rd party panel of doctors found that had I started taking those other drugs that I would have ended up having flare ups of shingles (shingles was caused by my autoimmune disease as well). After my approval of Otezla, I went to fill my first prescription and was told that the insurance company covered $1,000 a month, but the total cost was $3,000 a month. The company had a program where I answered a few questions and they would cover the rest! Thank GOD! Because even after all my work to stand up for myself, it was still completely unaffordable for anyone! However that program only covered 9 months of free copay. This is insane to think that I would have to get off the meds for 3 months, suffer through the symptoms of my autoimmune disease, and try to manage running a business and being a wife and mom until I could reapply for the free copay again. I tried that. I didn't make it more than one month off my meds before the symptoms became unbearable. Hopefully there will be some other free copay questions I can answer when that 9 months is up.

After her immune suppressive drugs started having less effect and were no longer working effectively against Crohn's disease, my wife was switched to other progressively more expensive drugs to see if any of them worked. After several different drugs were considered, she was prescribed Humira, which is the most expensive drug regularly prescribed (I think) and it almost killed her with some of the worst side effects you can get from it. We're still a little worried about long term side effects. The cost of the drug almost killed our comfortable life.

The price of the Humira prescription was so outrageous that most people can't even afford it.
She had Medicare, and supplemental coverage and I can only imagine how much the insurance companies paid for the Humira.

After the horrible side effects appeared, she was advised to stop the drug and discard the unused auto injectors that were unopened. We contacted the pharmacy and they advised the unopened Humira auto injectors valued at more than $30,000 could not be returned or reused for another patient. Regardless of the cost, the efficacy of the drug, the waste and use of the dangerous drug with horrible side effects, is an experiment every time that it is prescribed. For some people it becomes a choice of do I try something that could save my life, but risk death if an adverse side effect happens? Or do I choose to spend money on a prescription instead of other things like rent, food, vacations. It's mind bending that some get what they need easily and others have to fight hard to get something that could save their life. While the waste of unused, unopened drugs is sad, it is very common. Is this the best we can do as a society and modern civilization? We think not.

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As a dialysis patient with end stage renal failure, I'm on Medicare in addition to my work-provided insurance. One of the side effects of dialysis is hyperthyroidism in dialysis patients. This is usually treated with an injection of Parsabiv at the end of treatment. However, around 6 months ago, my care provider decided, as a cost saving measure, to switch to a pill that I take, which, despite their best efforts, makes me nauseous every time I take it. This was done because the insurance companies didn't want to pay the high prices for Parsabiv when a pill "can do the same job for cheaper". Because of this, I now have to decide..."do I deal with being sick 3 days a week, or do I not take my meds?"

I am a senior who worked hard all my life so others could get rich and I live on a just over the middle class bottom edge. My drug costs are over $1,000 per year, even with insurance. That is besides all the meds we both need. With the rising costs our rent is over 33% of our income and we live in a very modest apartment. We are only 2 of many who are effected by high drug prices (and we use generics, if available) and our story is very mild compared to most fixed income seniors.

I take prescription drugs. One is $3.30 a month at one pharmacy, the other is $10.00 a month through an online pharmacy. The taxpayers do not need to be paying for this. I do not want to be paying for this. Guess what? Money does not just appear by magic or grow on trees. The companies will just raise the prices for everyone to pay for this.

My teenage daughter is type 1 diabetic. Insulin is her 'super women juice' that keeps her strong and alive. We are fortunate to have dual health insurance, but even then costs of insulin and supplies mount.

My daughter has a friend whom is also type 1, whom will attempt to stretch out her dosage or not take it as insulin in order to make ends meet. This makes her very tired and can lead to serious short and long term medical issues. In emergency situations, we have provided her an insulin pen, although we know this is not advisable.

This disease is draining enough with the daily routine, physician appointments, and prescription ordering. Please look into why the cost of insulin is so high. It is my understanding the ingredients are inexpensive.
Making insulin more affordable is the one action that will make the most impact.

The state will save money in the long run, as all the secondary illnesses that arise from people who are forced to ration or thief insulin. Thank you for your time.

Over time, I have experienced both an increase in copays and an increase in prices for many medications. I am now lucky to have Medicare to cover most costs, but realize that drug prices are spiraling out of control because Medicare will not negotiate prices with Big Pharma.

I have an elderly aunt and uncle and a neighbor that have to go with out very important medication (heart pills, diabetic meds, blood pressure pills) due to the high cost and they can't afford it. This is not right.

I am completely satisfied with drug prices. I have access, even when I was on extreme poverty, even as a self supported single patent, I afforded anything I needed by working full-time. I however DO NOT want to pay for someone else's. The only things I struggled to pay for was prescription glasses, dental, dentures, and mental health care.

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I was recently prescribed Eliquis, a blood thinner. Apparently, I need to be on this drug indefinitely. Even with my Medicare Advantage Plan insurance, the cost is $41/month. There is no generic, and I asked my physician if there are other alternatives and he said this is the only drug of its class for my condition. For people who need to be on daily (or twice daily in my case), it seems that we could find a way to charge generic prices when there's no generic alternative. How do countries with a single payer system manage this? Could the drug be obtained from Canada or Mexico at a more reasonable price? I know there are people who have much worse medical conditions than I do, and I don't know how they manage the cost of their medications.
The inhalers that work for me are not on my formularies and thus way to costly.
They are absolutely ridiculous. My wife had medicine prescribed by a vet for our dog. The local pharmacy charged her $150.00. The pharmacist later contacted us and apologized to us for charging us the HUMAN price. The dog price for the SAME drug was $12.50 from the same pharmacy. So, why the hell are human drugs so much more expensive? We are being ripped off by unnecessary mark ups! It's because the healthcare system is a for-profit criminal enterprise that completely rips off customers. And the federal and state governments are complicit in allowing this to occur.
My family has always gone to independent, family-run pharmacies. Both in my town were shut down and bought out by a chain pharmacy. We moved to the next town over independent pharmacy and that just got bought by another chain pharmacy. Even another local store is now bought out. Our insurance company won't cover any prescription unless it is filled by their own mail order. How is this legal?
The cost of my loved one's Rx was more than he could afford, but he did not want another stroke. He went without buying food or paying the electric bill, to purchase Eliquis.

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I have a disease which has required drugs from a compounding pharmacy and many nutritional supplements rather than traditional prescription drugs. These medications are standard treatment for my disease and have absolutely been the difference between me being able to function normally or being completely disabled and unable to walk or write. As a result of the lack of coverage by my insurance company, I have had to spend over $15,000 this year in uncovered drugs for treatment of my disease (not to mention $20,000 in uncovered medical costs thus far, with an expected year end total close to $35,000). For example, I also had IV treatments, such as iron, that my insurance has not covered at all. I was diagnosed with severe anemia as a result of my disease and could not climb a flight of stairs without the iron infusions. This cost me $1,200. My insurance applied forty CENTS towards my deductible. Yes, forty CENTS. I am lucky and blessed this year to be able to afford $35,000 in medications and treatment out of pocket this year. I don't know what next year will hold, and that is terrifying. I also know that there are thousands of people with my disease who cannot afford to do this out of pocket. The cost to our communities is HORRIFIC when someone cannot work, cannot get medical treatment, and is completely disabled - and a medication or treatment is right there, available in our community, and not covered by insurance.Please also note, the one prescription drug I was given for my disease, and that was covered by my insurance, sent me to the emergency room and I had a $2,000 bill for the emergency room. How is this cost effective?Please add coverage for medications that are compounded and nutritional supplements used in the treatment of diseases. This is absolutely necessary and needs to be recognized and supported as valid treatment.

My medical coverage does not cover Dulera, an inhaler. I checked with two pharmacies - they charge $1,000 for one inhaler. I went without.

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My wife and I are both endocrinologists and most of our patients are on insulin. This is not a problem for OHP patients and for most patients with private insurance, but for many with no insurance or a high deductible, the cost of insulin can be overwhelming and often requires that they eat less in order to need less insulin, or let their blood sugars go high. Some end up in the hospital with DKA [diabetic ketoacidosis] from running out of insulin. Some on Medicare with limited income end up unable to pay their rent and buy insulin. The cost of insulin has increased from $45 per vial in 2003 when we moved to Oregon, to $450 now. One of my patients has family in Canada and goes there 3 times a year, where she can still buy the same insulin manufactured in the same plant in Indianapolis, but still it is only $45.25 years ago my wife developed CIDP. The treatment is IVIG, the cost of her medication is now $6,000 per month. She is on propranolol, which has gone from a copay with a Medicare Advantage Plan of $10 to now $65.I have asthma and my inhaler has gone from a copay of $10 to $65.Three years ago I ended up very ill at the hospital for 3 months. Afterwards, the antibiotics I needed cost several thousand dollars. I developed AIHA and now need a large dose of IVIG every 28 days at a cost of over $8,000 per dose.I was forced into early retirement in 2018 due to medical complications. At that time, I had nearly $900,000 in my IRA. Now it is less than $500,000. Of that over $300,000 was medical expenses not covered by Medicare.

I started taking a Tier 3 prescription in 2014. The initial cost of this prescription was covered with a reasonable copay and benefit program from the manufacturer. My insurance carrier processed the claims and even though the prescription was over $4,000 a month, I was only responsible for a reasonable copay.

When I switched carriers, my insurance stopped processing the claims with my prescription benefit program. Now I am responsible for paying out of pocket $6,000 a year and am completely at the whim of the benefit program, which is not used to dealing with individuals and very hard to communicate with. In theory I should be fully reimbursed for the out of pocket expenses, but I have had to charge these upfront costs on my credit card and wait, sometimes months, paying interest, calling repeatedly, to be reimbursed. I live in constant fear that the reimbursement program will decide to stop helping me, as they have no legal requirement to do so, in which case I would be out thousands of dollars each year.

All of this, and the cost of my meds keeps going up by sometimes hundreds of dollars from month to month. I now have had to reduce the number of pills I take to lower my financial risk and spread it out over multiple months. I now pay almost the same amount for half of the number of pills that I originally was prescribed, as I did when I started these meds. When I started this medication, it cost around $4,000/mo. If I were taking the full amount, it would now cost over $6,000 each month. The cost is increasing so rapidly it outpaces my rent increases and that of any other expense I have.

As a veterinarian, I can purchase many of the exact same drugs as are prescribed to humans for pennies on the dollar. They are produced by the same companies and often distributed by the same supply companies. The same scenario applies for many orthopedic implants, instruments and medical supplies. The mark up for human use is many times a factor of 500 times more! Your committee may want to ponder these facts.

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I have a chronic condition that must be treated with two Rx. One is relatively expensive, about $750 every quarter or which I pay about $200. Recently I got notice from my health insurance company that they were no longer going to cover that drug. They said they would cover a list of generic drugs that they determined would do the same thing.Before I started taking the expensive drug 15 years ago, my doctor and I tried two generic drugs which did not help. The two are on the list. I have appealed their decision.I see my specialist doctor at least once a year, sometimes twice a year. We have been generally pleased with the outcomes. I am very displeased with the actions and decisions by the insurance company. They are not licensed care providers. It seems inherently wrong that uncertified people who do not have your chart and have never given you an examination can interfere with your health care. From discussions with friends and family this is not an unusual situation. I ask for your assistance with this type of medicinal interference with our health care.

I am a mother and a retired nurse. Last year, the prescription I use to manage my diabetes, Levemir, cost me over $3,000 out of pocket.

I am on Social Security, Medicare, and supplemental plans for Medicare Part B and prescription drugs. My income on Social Security is limited, and a lot of it was going toward affording the drugs that keep me alive. Fortunately, I have recently been able to switch from Levemir to an oral medication, which costs me less out of pocket. I am more fortunate than most, but spending over $3,000 a year on prescription medications was a huge financial burden, and that burden remains heavy in my mind. To afford these drugs I had to cut the number of trips I took to visit my daughter and her family. I never take vacations for leisure and I have no wiggle room in my budget. I'm living as frugally as I can and I'm still struggling because of drug prices.

I am a retired nurse with chronic dry eye syndrome. I have been prescribed Restasis for some time now, but I haven't taken it as prescribed due to the horrendous cost. A full dose would cost me more than $910 per year out of pocket. It is so important that I take the drug regularly so that I can keep my corneas healthy. Without proper treatment, I could do permanent damage to my vision.

But high drug prices don't only affect me. My husband must take Xarelto as prescribed for AFib and to prevent fatal blood clots. It's $304 each month total, with an out-of-pocket cost presently at $130 a month. We should not be getting priced out of the drugs we need to survive.

My significant other was diagnosed with leukemia three years ago and received a bone marrow transplant. He is currently on several medications, and the most expensive one is Jakafi. If we didn't have help from a patient assistance foundation, we would not be able to afford it because it would have cost thousands of dollars out of pocket every month. For now, we are able to afford our medications through insurance and patient assistance, but we are worried about whether this is sustainable.

I think that the pharmaceutical companies are charging these exorbitant amounts of money because they do not care that if people can't afford their medications, they die. It is all about padding their pockets.

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I am a two-tour disabled Vietnam combat veteran, so my family has health coverage from CHAMPVA. But even with insurance, we've had trouble affording my wife's medication for chronic hepatitis C. She is currently trying out a new drug, Mavyret, on a recommendation from her doctor. Mavyret costs $12,000 for a 30-day supply. We were unable to afford the out-of-pocket expenses of $3,000 annually, but luckily, we qualified for financial help from a patient assistance foundation. She has been on Mavyret for two months and is waiting for test results to see if it works for her, but she will die without relief for her condition. Everyone we've contacted for help with drug costs has said that our family has done our duty for our country only to see the system let us down in our time of need. High drug prices are killing the people our great country is supposed to protect.
At 85 years old, I am blessed to have quite good health aside from the occasional issue. One of my most recent issues was a blood clotting problem that was exacerbated during travel. Thankfully, the blood clotting didn't endanger my life, but I nearly fainted when I saw the cost of the medicine my doctor prescribed me. When I bought my first bottle of Eliquis, the bill was for about $430 after insurance. The dosage that cost $430 was to cover just about a month's time. The bill was that high because I hadn't yet met my deductible for the year. The next bottle was substantially less, a little over $100, but I know that that is still a lot of money for many people - and it is a lot for me as well.
Even with drug coverage, because of the high pricing on my medication I reach a "donut hole" [coverage gap in Medicare drug plans created by drug plan limitations] after just 6 months & then have to pay 25% of the original cost of over $1,400.
I am a Stage IV ovarian cancer patient. My oncologist has prescribed two drugs, Zejula and Keytruda, to treat my cancer. My insurance denied both prescriptions. I don't know the price of these two drugs, but I'm assuming they are costly hence the denial. Nothing is going to cure my cancer, however these two drugs will extend my life. I have confidence that my oncologist is making decisions that will benefit me. My gynecologic oncologist is highly trained and has years of experience treating ovarian cancer patients. Why is my insurance overriding the decisions of my oncologist? Exclusions for pre-existing conditions was eliminated with the ACA. However, it seems the insurance companies have figured out a simple workaround. Denial. Denial of treatments. Denial of vital medications. Of course, you can appeal their decision but patients rarely prevail in the appeal process.

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This pertains to seeing, as a care provider, the suffering I have seen with folks needing medications.I have seen and heard folks saying 'Oh my gosh, I have not enough money to get my needed medication' for whatever there health problem is or was.'So, I will not be able to eat well again, and what money is left for electric and housing will barely make ends meet. I do not qualify for outside help due to my retirement amount just barely over what is allowed for income and help.''Can you please take me to food bank, so I can get something to help with my food need?''I cannot have my heat on very much, as the cost of meds does not allow for that.'Also, heard 'I do not take my meds as prescribed daily, I skip to make last longer'. How dangerous is this? Very, very dangerous, as their health can and does fail. More problems can arise with this. What can they do with these outrageous prices?? It has been mentioned perhaps they get a hold of prescription companies to see if there is a helpful financial assistance med program. Often times there is not with needed medication. There has been times there has been some relief of the needed meds.There is no reason this should be allowed nor happening in our great United States of America. Thank you to President Trump this is being addressed and changed. God bless America.Our people should not stress for their needed meds. They did not make this happen to themselves or wish for conditions and the outrageous prices for meds.We the people need to stand together united and say enough is enough. The meds help keep long term issues at times at bay, keep them from long hospital stays, or not having quality of life, and possibly becoming deceased.I'm retired now and spent many years with the folks whom were in rest homes, hospitals, and their own homes. It was a calling not a job. Heart breaking to have seen and heard and hear in lines at the pharmacy, the dismay and 'oh my gosh no way I can pay that'. Right then and there could start another health concern - stress, anxiety, dismay. What can I do?

I am fortunate not to have to use expensive drugs. However, as a former financial planner I know that medical costs are the leading contributor to bankruptcies and financial distress for individuals. Big Pharma argues that the cost of drugs is a relatively small part of the overall medical cost crisis in the US, but at the individual level, it can be one of the most devastating problems due to the limited insurance coverage (a giveaway to Big Pharma to let them into the Medicare program).

Prevymis is another extremely expensive drug. My wife required it for a bone marrow transplant and the Costco price for a 90 day supply was $17,837.94.

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My father, age 79, confessed that he is only doing one breathing treatment per day for his COPD rather than the two-a-day he is prescribed. He is trying to save money - a fixed income received from Social Security benefits. Although he readily acknowledges his part in his disease - a result of long-term tobacco use, he has been smoke-free for a number of years - I don't believe he should, in essence, be punished for not being healthier and/or falling into the trap of addiction. I also know that the reason he is trying to save money on his meds is because my mother has diabetes. He will sacrifice his medication to make sure she gets hers. My mother does not currently use insulin but he is afraid she will, and the more he hears about how much insulin costs, the more he will worry about the day when she might need it.

In addition to a rescue inhaler (albuterol), I have used a maintenance medication for my asthma for many years. In recent years (at least 5), I used Advair Diskus. This has resulted in me using the rescue inhaler less frequently.

Earlier this year, when I went to the pharmacy to get the Advair Diskus filled, it was going to cost around $500 (previously it was less than $50). I asked the pharmacist to contact my physician for another possible medication that was comparable. In the interim, I ended up using my rescue inhaler much more frequently...which makes my heart rate increase and disturbs my sleep patterns.

My doctor then wrote a prescription for Symbicort. The pharmacist processed it and it was going to cost around $350. I still did NOT get it filled. The pharmacist told me about a program with the drug manufacturer, so I signed up for that and it dropped the cost to about $150. However, instead of taking it as prescribed, I use less in order to make it last longer.
I have medical insurance with prescription coverage...yet am paying massive amounts just to be able to breathe easy.

I have asthma. In order to breathe, I have to take a daily asthma medication that costs $240 per month. The pharmacist always asks me if I know how much the prescription costs when I go to pick it up. The option is to not breathe. In June I was diagnosed with a DVT blood clot. I now have to take Xarelto, which costs $430 per month after my coupon. Without the coupon it would be nearly $600 per month. Between these two prescriptions, I am paying the equivalent of the rent for a studio or 1 bedroom apartment. By the time I add a house payment on top of these two prescriptions, I don't have much left to live on each month. Certainly not enough to pay for health insurance, which is another $400-$500 per month. And that doesn't include prescriptions. I still have to pay those out-of-pocket. Something is wrong with a system that is creating "working poor" who are at risk of being homeless just to be able to pay for medication.

My adult son had asthma his whole life and continued to suffer with it in his 50's. For an extended period he did not have health insurance...and could not afford the cost of the one inhaler medication that made it possible for him to keep working. The $427 per month that I paid for this Rx kept him alive until lack of health insurance coverage caused his death at 57.

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I fell through the "donut hole" [coverage gap in Medicare drug plans created by drug plan limitations] in August this year, so the price for my COPD medication went up from $37 a month to over $130 a month. If GSK had not offered me free medication for the rest of the year (I had to submit proof of need), I would not have this medication for over 5 months this year. I take few drugs (only 3), and they cost me (after my Advantage Plan) about $80 a month. I am fortunate, but still struggle with income of $1,780 a month and rent at over 1/2 that amount to pay for them. This is the only pharma to offer me any help since beginning Medicare over 10 years ago.I would likely not have survived till the New Year without their program for Medicare recipients who fall through the donut hole. State support programs place me over poverty level eligible for help - which is another issue.

I have health insurance. I also have asthma but am otherwise a healthy person of age 77.
My asthma is well controlled because I use an inhaler daily and avoid triggers.

Medicare pays my insurer for me monthly but I use very little from the insurer because I sleep well, am conscious about what I eat, and work out three times weekly at a local gym.

The only thing I have needed from the insurer in the past year is an asthma inhaler at a reasonable cost. To get an inhaler via insurance would cost me a $245 yearly deductible plus $100 each month. This is a total of $1,445 yearly in addition to the money deducted for Medicare each month from my Social Security check. How did I handle this? I searched on-line for a pharmacy discount card until I found a discount program, which allows me to purchase the needed inhaler at a local pharmacy for $45 monthly, a yearly savings of $950. Many seniors do not use computers or know how to do computer searches, so they are likely paying prices they cannot afford in order to obtain the necessary prescription drugs. If I can get this medication for $45 a month, why can't the insurer sell it to me at a reasonable price?

I am thankful that I have relatively good health care and prescription insurance; however some key medications that I take have a $70 co-pay. Without insurance I don't know how I would pay for these things. With insurance 2 monthly prescriptions with a $70 co-pay is hard. There have been times in the past where I was unable to afford my asthma medication. There have been times where I have had to make my inhaler last longer than it should (reduced dosing). I have also done asthma studies in the past in order to be able to afford my medication and survived with drug samples only. When those were no longer available I have had to pay the $70 co-pay.

My insurance also requires 3 month refills on most medications, so having to come up with the large co-pay for multiple months for multiple prescriptions can be difficult. Preferred drug options for my prescription plan require me to purchase only certain medications for coverage. Recently, I had to change my rescue inhaler to a different type based on the insurance requirements. I don't feel like this is as effective as other medications I have taken but I really have no choice. Also at one point my albuterol inhaler was affordable and now as new formulations become available there is no longer an affordable generic option.

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My son was diagnosed at age 16 with type 1 diabetes and was in ICU with diabetic ketoacidosis for two weeks until the doctors got his blood sugar under control. This disease is still greatly misunderstood in this country. Even the ICU doctors said nobody pays for diabetes supplies and prescriptions out of pocket because they can't. No one could afford it. So you either have insurance or you get OHP. Period. And that's not easy. His Lantus and Novolog are over $1,800 a MONTH, just for those insulins he needs to live. And he's living with me still, four years later, because he's a rare "brittle" diabetic that eats super healthy but can have his blood sugar drop to deadly range at the drop of a hat. His A1C is 5 [average blood glucose levels], which proves he's doing incredibly well with his diabetes, but he could die so, so easily just because his tiny body isn't working right. And I pay $400 a month for his insurance so he can get at least some of the prescriptions for his diabetes, but some things are insanely expensive and difficult to get. Did you know the pumps everyone talks about aren't even available at a pharmacy? Every diabetic has to go through a mail order process to get the pumps and the supplies. We use [supplier]. Read the reviews online: they're horrifying. Add to this nightmare with crippling depression and guilt for the packaging and needles contributing to our garbage problem in America, and the emotional toll the disease takes on the diabetic and anyone close to them who helps manage the disease. When my son turns 26, he can't be covered by my insurance anymore. But in this country, in this era? Will he get insurance? He's union, for gods sake, but his medical insurance can be dropped at work any time the boss gives him 32 hours in a week instead of 40. He would die if he couldn't pay for his meds at that point. So we can't even risk putting him on insurance through his work, because it could kill him. We are, every one of us, one uninsured illness away from homelessness. It's a nightmare.

The last time I renewed my insulin prescription, the form from my pharmacy stated I saved $1,276 because of my insurance. How can four (4) vials of insulin cost $1,276? This is outrageous! If I was on Medicare or Medicaid what would the cost be to the state? I can see why folks without insurance die because they cannot afford to take their medication as prescribed by their physician. National news reports insulin prices have increased 1000% over the past few years, and that is for generics.

I am an insurance agent and several of my clients have experienced mid-year out of pocket increases, primarily for the diabetic medications. They have no choice but to pay these increases, however why cannot they have some advance warning? When the consumer has a co pay of $100 each month and then suddenly it jumps to $300 per month, that is alarming. Several people are finding ways to purchase medications in Mexico and Canada at a fraction of the cost we charge in the USA.

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Have experienced a minimum 300% mark up in cost of insulin over the 20 plus years since diagnosed type 1 -- insulin DEPENDENT. Every time there is an improvement made to long or short acting insulin it goes in the most expensive tier in pharmacy insurance plans and is prohibitively expensive for anyone paying out of pocket (unless you are ultra-wealthy and not paying 40% of your take home for housing...). I see cost changes only really being made to older led effective insulin, such as Lantus or Regular and NPH. Yet physicians have all this data about how more efficient insulin (or chemo...or cardiac drugs...or blood pressure meds...you name the medical condition) work better, faster, longer and help patients achieve better outcomes. But patients don't truly have access to these drugs unless they are wealthy. Also, companies are allowed to offer intrusive "coupons" to help drive the cost down to closer-to-general-consumer levels, but require that patients provide their personal health data in exchange. I am tired of being forced to give my personal health information in exchange for affordable life-saving medicine. I should not be a forced study guinea pig because I am trying to best manage my chronic condition. There are myriad data breaches and I am the one at most risk if my information gets leaked/stolen/shared. I should not have to choose between managing my limited budget and managing my life-threatening disease to access the care that best treats my condition.

I have two stories to share; one is as a diabetic nurse I often found my patients would simply go without their diabetes medications because they could not afford them. We had a pharmacy at our safety-net clinic that could provide lower cost medications but even with our lower prices many patients could not afford insulin and other diabetes medications. I remember several times having a type one diabetic call me as they were out of insulin when our pharmacy was closed. I would call several local pharmacies to try to find an insulin preparation that my patient could afford to last them until they could get a refill with us. I had to spend hours sometimes trying to find a low cost insulin preparation and then come up with a whole new insulin dosing schedule as this different insulin could not be dosed the same way as the preparation the patient was on previously. I could not simply have the patient wait and fill their prescription when our pharmacy was open because type one patients will die without insulin within hours to days.

On a personal note I have asthma and I saw the asthma inhaler that I need to be able to breath go up in price dramatically when the company got a new patent just because they had to use a new propellant. At one point my inhaler (with my insurance) cost went up to $90 per inhaler (usually good for about a month). I could afford this but wondered how people with lower incomes could. Many people with asthma are completely dependent on their inhalers to live. In my case I tried several other brands and none of them worked so I had to pay the $90 each month. Had I not had insurance that price would have been $415.00! How is that even possible? Does that mean people without insurance should just end up in the ER because they can’t afford their inhalers? This inhaler (Flovent) is not new it has been on the market for many, many years but it keeps getting new patents and the company that produces it prevents generic brands from coming to market. How can life saving meds be available just for those who can afford them?

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I have insurance and am still paying over $200 a month for my insulin. I don't qualify for any of the discount cards because I am a Medicare patient. The amount takes a big hit from my income.
I take a GLP-1 agonist called Bydureon. This helps to control my blood glucose levels in conjunction with diet, exercise, and insulin. At the start of the year is when I struggle the most to fill that prescription, because a one month supply without any discounts or special funding, is over $700. It's a prescription that I often have to forego at the start of the year, until I've met my deductible. This is something I sadly prepare for by not taking all of my doses in November and December, so I can carry the effects a little longer into the new year. My doctor's office has had to help in the past by provisioning all of their samples so I have a little more.This shouldn't be the norm for prescriptions, and if I'm struggling with a GLP-1 agonist like this, I can only imagine how others with worse insurance or no insurance are struggling with just insulin.I get that insulin prices have skyrocketed over the past decade as improvements have been honestly made -- we now have degludec, two grades of glargine, and detemir in addition to the regular and NPH formulations, and some seriously fast acting formulae as well. We have better delivery systems, designed to remove the guesswork from measuring.The improved outcomes are great, but not so much when no-one can afford the inflated pricing.
Our son, who is now 22 and on our health insurance plan, has type 1 diabetes. We have a plan that has a co-pay of $30-$40 for his insulin and supplies. Through my employer, I have a high deductible plan and an annually funded VEBA to offset the cost. Technology has been making it easier for him to manage his blood sugar and for the most part, he is getting the supplies and insulin he needs and it's affordable for us. We worry about him having to spend $100, or more, every month once he's on his own. In addition, last year he received a new meter and sensor and, at that time, we were told it was only available through one company, Byram. This company coded his new sensor and meter "durable medical goods" and our insurance would not cover it. We ended up paying about $800 for 3 sensors ($226 per sensor). He needs 3 per month--they last for 10 days. I spoke with Byram and my insurance company about our prescription plan covering this as it should. Both told me "durable medical goods are not covered and [we] they can charge that much." We switched the prescription to our local pharmacy and paid the co-pay of $30 for 3 sensors ($10 per sensor a difference of $256). We shelled out over $1,500 for sensors and although the insurance company listened and told me "we'll see what we can do to get your money back," I never received anything and that was over 7 months ago. Our son got what he needed, but this expense took almost half of the $3,000 that was in the VEBA for the year. In my opinion, Byram needs to be investigated and this type of "coding" and "naming" things to rake in more money is just morally and ethically wrong. This equipment is needed by people to be alive and healthy and why our own government allows this kind of fleecing based on medical conditions is just heartbreaking and, well, cruel. I want things to change for our son to ultimately be cured, but until that day, he, and millions of others, need insulin and supplies and they should not be punished with having to pay sky-high rates and spend energy fighting with insurance companies. People with chronic conditions and injuries pay every day with compromised health. Please do something to regulate prices and insurance companies. Please investigate Byram, too--a corrupt, heartless company that should not be allowed to profit from people's illnesses and injuries.

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I am insulin dependent. I have also been able to take some of the new class III drugs including Victoza, Trulicity and Ozempic. They work. But I've had to give Ozempic up so that I could eat and pay rent. I had to wait until I've reached the catastrophic level outside the Medicare donut hole [coverage gap in Medicare drug plans created by drug plan limitations] to take up the medication again ... temporarily. When the cycle starts over again, I will give up Ozempic and cut down on food so that I can take insulin, which is also Class III drugs. That will be more insulin than what I'm taking currently. I know I'm not alone.

I take care of patients from a variety of economically and culturally diverse backgrounds, with all different insurance types. My patients can no longer afford basic medications that they used to be able to afford. The two most egregious examples of a prescription drug market that is completely dysfunctional (and therefore needs to be regulated) are insulin and inhaled medications for COPD/emphysema/asthma. Insulin has been around for +100 years, yet there are no readily available generics, diabetes is increasing, the market for insulin is huge and expanding. And yet the price for most insulin types has tripled in the last several years. That doesn't make basic economic sense - unless there is illegal price gouging or market manipulation occurring. It is common for my patients to spread out their insulin by reducing their doses, to skip doses completely, or to not pick up refills because they can't afford the hundreds of dollars for the life-saving medication. This is now routine in practice - a big change from 10 years ago. Evidence clearly shows COPD/Asthma medications are VERY effective at treating and reducing symptoms of these common illnesses. 5-10 years ago, my patients could routinely afford their effective medications. Now, again, despite a "thriving market" (large population), the prices of these medications has increased +100% routinely my patients simply cannot afford these medicines. So they don't pick up prescriptions, spread the use of them out - and sometimes end up in the emergency room in the middle of the night as a result - their lungs so tight, they're in the ER desperate to get an emergency treatment and feel their lungs move enough air. Is this acceptable in a first-world nation that purports to value equity?? This should not be acceptable for a Division of Consumer and Business Services that is supposed to protect consumer and ensure fair market-based business can occur. Please take action.

I am a long-term migraine headache sufferer. A lot of the preventative drugs for migraines have negative side effects or are not helpful. There are two drugs that my doctor thinks that will be especially beneficial: 1) Aimovig 2) Botox injections for migraine.
Aimovig is over $500 a month, and my insurance will not cover it. Botox is $1,500 a treatment, but because of the nature of the toxin, it will never become generic. Allergan has a virtual hold over the market. (And I would be using it for medicinal purposes—and not for beauty purposes.)

I also recently went on generic Cytomel for my thyroid, and this drug runs $78 for a three month supply compared to $15 for a three month supply for preferred generics. It's nothing compared to my migraine medicine, but it all adds up.
The dilemma is what does this profit gouging do to benefit the public? What is the public good for these high prescription prices (that the government cannot even negotiate on behalf of the public).

It's time for reform in the medical, pharmaceutical, and insurance industries. Any costs have to have a public benefit, and the costs cannot continue to pad ever increasing corporate salaries, perks, and dividends at the expense of the general public.

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Last year I was laid off from work. I purchase a high deductible health care plan as it was the lowest cost option and thought it would provide a prescription option as I require 3 prescriptions to either stay alive and/or healthy. I used a discount program to understand the cost difference between pharmacies. I also found out one location had its out drug card for an annual fee. This drug card saved me an average of $75/month while the insurance would have only saved me $15 below retail. I see that the pharmaceutical companies play a game that isn't fair to the insurance companies, states or consumers.

I had been taking brimonidine tartrate, the generic version of Alphagan-P® eye drops for glaucoma. My doctor felt we needed to bring my intraocular pressure (IOP) down further, and suggested we try Alphagan instead.In an odd reversal of roles, it was I asking "A generic is said to be therapeutically equivalent to the brand which inspired it, is it not?" She said that in her clinical experience about a third of her patients get better results with Alphagan. So I switched, and my IOP dropped three points (33%)! At that time Alphagan was a tier 3 (preferred brand) covered by a higher but fixed copay. Preserving my vision was and is my top medical priority, so I felt a higher copay was justified, and agreed to switch.But the shameless thieves at Allergan (maker of Alphagan) have since so relentlessly inflated the price of Alphagan that four out of five plans I looked at during open enrollment in 2019 now list it as a tier 4 (non-preferred brand) covered by an even higher copay which is NOT fixed, but expressed as a percentage of inflated list cost! Not only does that guarantee a much higher copay out the gate, but if Allergan decides to increase the price even more during the plan year, one or two or more times, the copay does not remain the same (as with a fixed copay) but increases INSTANTLY, EVERY TIME!Returning to the generic version is not an option in this case, since my doctor has already determined, contrary to conventional wisdom, that the generic is NOT therapeutically equivalent to the brand!

I am a 60-year-old female on disability for lupus, kidney disease, heart defect and more. I am on 10-15 meds at any given time. As you can imagine this gets confusing— and expensive. It would be helpful to have a way to schedule medication refills so they would be refillable at the same time. I have so many meds that I set them up a month at a time. If I cannot refill some for a week or two out that means I cannot set them up at the same time and the likelihood of errors is increased. Also, the cost varies from month to month if they are not all refillable together and this is a hardship on low income folks.

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1) My husband was having severe nerve pain and "zaps" of pain, in his upper thigh, lower back and down the leg. He has had previous back problems and surgeries, but this pain was more severe and we were waiting for a time when surgery on a newly damaged disk (he had infection, then pneumonia, then the surgeon was out of country for a month). Our insurance company denied coverage for Lyrica, which our family doctor prescribed for him. The proper preauthorization was done, and less expensive drugs were tried, without much help. By the time multiple appeals were done, and they finally approved coverage, it was within days of his surgery, so we didn't spend the (still) high cost to get the drug. He just lived with the pain. 2) I myself have had irritable bowel syndrome for many years. The past year and a half or so, something has been much worse and I was spending 5-8 times in the bathroom with it every day. Many tests had been done by my gastroenterologist after I was hospitalized twice in one month (the first time in ICU for 4 of the days, due to sepsis) - both times were with small intestine inflammation/infections. Finally tests for SIBO (small intestinal bacterial overgrowth) were positive, and my doctor prescribed Xifaxan and Neomycin, the most commonly used and most effective treatment. My insurance denied coverage. An appeal was done. Again denied. I was treated with a different, less effective medication (Augmentin) and it didn't help much at all. After a 3rd appeal, my insurance finally made an exception to cover the correct medication. So I had months of waiting for that, still suffering. The reason they didn't want to cover it, I'm sure, is that it's only used for 2-3 illnesses, and the two week treatment would cost $2,000. It's specifically used for this because it STAYS in the gut so it works better. But because of $$$$$, it took 3 appeals and all this time for my insurance to cover it. Thank you.
One of the drugs I take, Synthroid, I have to stay ON BRAND because I don't do well on the generic versions (and all doctors of hypothyroidism pretty much advise you to not switch when you find one that works for you). I've had to increase my dosage recently, which means I'm taking two different Synthroid pills per day, so I'm paying for two prescriptions each month. My insurance does not cover this in my plan. I am currently paying, out of pocket, over $100/month just for this daily pill that I need to keep taking so that I don't stop being semi healthy. I am also on Enbrel - auto injector click pen. This prescription IS covered by my insurance, but I am married to someone who is from another country. I cannot buy more than one month of this at a time, and I do need to travel overseas for a couple of months at a time. If I did not have insurance, or I need to go out of town, I am on the hook for well over $1,000 for a month of click pens (1 a week). This is making travel impossible due to the high cost.
I was diagnosed with interstitial cystitis and the only medicine that I haven't tried is Elmiron but my cost after the insurance is $400 and that cost is for every month. I went to every single pharmacy in our area to compare prices and every pharmacy was the same price within a few dollars. I cannot afford to pay $400 each month for a medicine that I can buy in Canada for $122 or in Mexico for even less. I do not have the ability to travel to those areas in order to get some medicine that could possibly help me, so I have to live in pain.
My doctor felt I needed a new anti-depressant because the current one wasn't working. She prescribed a relatively new drug. When I went to pick up the Rx they said it would be over $700 for a one-month supply. How can anyone afford that?? Needless to say, my doctor prescribed something else that costs about $16/month. Fortunately! I just have to add that it is criminal that insulin is so expensive that people cannot afford this life-saving medication. Criminal!!
Hepatitis C treatment: First time cost was about $90,000 with Harvoni, second time was about $120,000 with Harvoni and Ribavirin, both of which failed. Third treatment was again over $90,000 with another drug (can't recall the name). That was over $300,000 total for all three treatments. The last treatment worked fortunately.

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I have gout, and take colchicine when I have flares. When I first started having problems with gout about 10 years ago, a 90-day supply (180 pills) cost less than $5.00 a bottle from my local pharmacy.

Now, I am on Medicare, and have an Advantage Plan. If I buy a 90-day supply using my insurance it costs me about $384.00. The $384.00 is my cost, not the total cost of this medication that has been around for hundreds of years. There were no development costs for this medication, it's been around for many years, like aspirin. We, the consumers, are getting price gouged in the worst way. I have started buying this medication from Canada, without insurance. My cost, which includes shipping charges, for 200 pills is just under $75.00. I would like to see the companies making and selling these drugs explain with a straight face why consumers should buy their products at all. And what, if anything, our state and federal governments are doing dragging their feet on rectifying this grossly out of control situation.

I was diagnosed with advanced ovarian cancer about 2 years ago. I underwent surgery and chemotherapy and entered a clinical trial sponsored by the Tesaro company, using the medication niraparib. The prognosis for my disease is poor, most people die within 2 years. So there was no question that I'd try the niraparib. I haven't had a recurrence and I know niraparib may be the reason. I'm very grateful for all the efforts to develop this drug. I understood from my doctor that the likely recommendation would be to continue this med indefinitely after my participation in the trial ended. I was notified by SSA recently that I'll begin Medicare enrollment in Feb. 2020, 2 years from the date I started Social Security disability. So I began the research to choose my Medicare supplement or Advantage Plan. I learned that this drug costs appx $2,500.00 a month and that any plan I chose would result in paying a minimum of $6,000.00 a year out of pocket for the med in addition to out of pocket expenses for other medical expenses. I don't have $6,000.00 a year available and it seems this drug is vitally important. So I will be looking for employment. I feel fortunate that I'm feeling well enough to work at something. However, I'm concerned about overextending myself as I fight this disease. I think of others facing the same or much worse, who may not feel well enough to work. The thought strikes me that a society which doesn't take care of their own sick, is a sick society. I think it's barbaric that we don't have a safety net to help each other weather the storm of illness. Feels like when a person's sick , they're kicked when they're down facing the financial strain of the illness. For this reason I support universal health care.

My wife has been phoning a pharmacy in Canada for eye medication at a third of the cost of U.S. While visiting in Victoria BC, Canada, we met retired American couples who moved there to be able to manage their health care. I checked on one of my medication and realized I could visit Canada and pick up medication and pay for the trip.

There was a drug my doctor prescribed recently that I found my insurance would not pay for. The drug was going to be $3,000.00 per month. The company that supplied the drug said there were discounts available and the drug would "only" be $1,000 a month if my husband and I made less than $60,000 per year. I did not get the drug.

My son was diagnosed 4 years ago with Hepatitis C and has been unable to get the medicine he needs because it costs $90,000 and his Oregon Health Care doctors won’t prescribe. They say he does not have enough of the virus in his blood and yet the disease is damaging his liver and kidneys. He feels they are just waiting for him to die. We finally gave up and sent him to Chennai, India, where the same drug cost him less than $3,000. This situation is just plain wrong! Makes me furious!!!!!

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I Pay a copay each month with private insurance through my wife. If I go on Medicare (which I can) I pay $2,300 in January each year and then $329 per month for the drug. My wife would like to retire, but I need private insurance in order to afford this drug. If I go onto Medicare, I will just have to stop taking the drug....Thanks.

My husband has stage 4 colon cancer. His doctor suggested Lonsurf as a treatment since others were not working. "After" Medicare & supplement, our out of pocket cost would have been $2,244.

I wish I could attend the hearing, but I can hardly walk due to horrible osteoarthritis in my right foot. (Will be having it fused in January.) I am and have been on biologics for 10 years. The prices are beyond ridiculous. I was on Orencia for several years. Price has reached $7,700.00 for 1 dose (had to have 1 dose every 4 weeks). Now I am back on Humira at one dose every other week (price is $2,000.00 per dose). Medicare with my supplement only covers 80%. My husband at age 66 has to continue to work so that I can be double covered on insurance (his pays the remaining 20%).

I had to stop taking a medication because insurance would not cover it and it was $500 for 30 days.

Tretinoin is used to treat acne but also to reduce sun damage to skin and prevent precancerous conditions. Yet it costs about $65 for a small tube of this creme, unless it's being used for acne. In that case only, it's covered by most insurance plans. This is a prime example of short-sighted price gouging, since the cost of treating skin cancers is vastly greater than this simple preventive creme.

I work as an infusion nurse, infusing biologic medications that not only improve people's quality of life, but save lives as well. I have watched the price of the drugs I infuse increase every year over the last 4 years. I know of one long term biologic that had it patent run out in that time. This means other companies can now make a "generic" or "biosimilar" as they are called in this class of medications. Another company has created this. I have not seen any savings for my patients and in fact, the price of the trade brand and the biosimilar and have increased. The patients are not considered, nor respected, in this pharmaceutical industry.

I have been so dismayed at the cost of drugs in the private sector (after 10 years in ER - not informed about cost or insurance) that I have considered giving up nursing in search of a career in which I can make a difference. I work hard to make a difference to my patients on a daily basis but it is hard to want to continue in a system so broken that it causes harm to the people is was created to help and protect.

I've read so many accounts of soaring must-have prescription drug prices. Drugs such as insulin are priced so high that diabetics are sorely pressed to afford it. I had a bad experience lately with a prescription drug, but my life doesn't depend on it. Timolol eye drops, to reduce pressure, increased about 150 percent, the last time I ordered this drug. The price had been $11.50 for years, at my pharmacy. The last time, it was over $28.00. I forget the exact price. The pharmacy employee told me that I could transfer the prescription to another pharmacy, which I thought was odd. So I asked her to transfer it to another and bought it for $16.00. The increase in price from $11.50 to $28+ is a rip off that I think probably has nothing to do with ingredients or demand, just an arbitrary price hike.

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I am retired, living on Social Security. My wife is still working. My SS gross is $14,000. It now takes all of that and dipping into my wife's pay checks to pay for my meds now. It use to be my SS would pay for my meds and there would be $ left over at the end of the months, but not any more. My wife's paychecks would pay our living expenses, now it is also paying for meds.
The Medicare part D is structured like a SCAM. Seniors are put in a damned if you do and damned if you don't situation, and this shouldn't be the way to help us with prescription needs. You are either compelled to pay every year from age 65 for an insurance policy for prescriptions WHICH DOES NOT PAY FOR THE PRESCRIPTIONS YOU NEED (Tier this and tier that and deductibles which RESULTS IN HIGHER COSTS THAN BUYING THEM WITHOUT THE PLAN). And if you don't agree to this extortion, then Medicare penalizes you A LOT OF MONEY FOR THE REST OF YOUR LIFE!!! Medicare and the insurance industry ARE ACTING LIKE THE MAFIA. In cahoots, extorting money from people. Same strategy. The federal government needs to contract with drug companies to have the lowest possible price for medicines, all medicines approved for public use, no tiers, and Medicare members should just buy them for those fair prices whether they choose to have an insurance plan for Rx or NOT.
My husband and myself became ranchers. This land is basically sage brush steppes in Eastern Oregon. For about 6-8 years we could afford our insurance .... Then when the price of health insurance for us and our 2 children rose to equal the price of our annual ranch payment, we had to drop the insurance. Luckily, we were a very healthy family.Now I am on Medicare (which I DO consider an entitlement since I pay ~$2800 annually for health insurance and paid forward for when I worked off the ranch for 15 years). I still do not have part D because my husband and I did not sign up for it 10 years ago. I am widowed, living on income from agricultural resources (land, sheep, and cattle) which I had to sell to live.I am still fortunate in that my drug prices have not risen out of control due to pretty good health (due to comparatively good health for my age). But ... how long will this last? If the fees for part D coverage are not forgiven my annual cost for Medicare coverage will rise to $7,600+!
It is unbelievable to me, that in a land of plenty we are being fleeced by corporations. The American dream died, not because of partisan politics but due to corporate greed. The cost of medications is one such example of the fleecing of the American people. The only reason the drugs cost as much as they do is because the company knows people need it, so they hike the price and fix it at a standard much, much higher than necessary for no other reason than to make more money. This needs to stop. There are many other countries that do not allow this, and are developed at or above our standard of living. In fact if you look at the numbers our country only ranks number one in two areas. The number of people incarcerated and the number of people that believe in a god. If this trend does not stop we will see more people die, more people become homeless and more people losing their already low income. With more automation on the way in the work force more than 400 million stands to lose their jobs in the next 30-35 years. If we keep the status quo, we are headed into ever more people having no home, and homes sitting dilapidated and empty. If we do not address this issue, including the issue of over priced medications, and run away corporate profiteering on the backs of the needy, those who are under employed and those who don't have enough we won't have a country left.

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I am a retiree after 30 years working for state government here in Oregon. I feel *so* lucky that insurance and Medicare, between them, cover all of my prescription drugs (at the moment, I'm only taking a generic blood pressure medication, and my co-pay is only a couple of dollars for each refill, which is a life-saver.) ALL Oregonians should have access to affordable health care and prescriptions, not just those of us who were lucky enough to have state jobs!

I take 3 different medications daily to stabilize my blood pressure and my hypothyroidism. I can afford them for now.

I am fortunate to have prescription coverage through my employer. My insurance has a pharmacy price look up tool so I can compare drug costs between pharmacies and it presents lower cost alternatives for me to discuss with my doctor. I don't think that tools like this are widely used. Further, the costs vary by carrier as we have dual coverage with an other insurance. It is very challenging to be an active consumer in this environment.

The prescription drug is for general people who need it to get better health, just like a certain food. Therefore it should be priced at affordable and reachable for the general public. I am sure the suppliers should have a proper margin to survive and be encouraged. We also can compare our pricing system to a better system in other countries. I believe America is very smart and can figure this out unselfishly.

Currently I am homeless and had a issue picking up prescriptions. The issue occurred when the hospital pharmacy could not roll the one time issuance of a limited need prescription and the pharmacy would not accept a voucher willingly.

I don't take any prescription drugs, but I am concerned about those who can't afford their medication.

I am a hard working woman in my early 30's. I have experienced having lulls in my medical insurance coverage between jobs. I have also experienced pay cuts just to be able to accept a job offering an increase to my prescription coverages. My partner who is a type 1 diabetic has shown me what his insurance is actually billed for insulin. Hundreds of dollars for vials costing, I'm sure, a small percentage of what they cost to manufacture. There has to be a percentage ratio cap to how much a company can charge for medications compared to their cost to manufacture them. There has to be a maximum.

I have type 1 diabetes and do everything I can to manage it well: check my blood sugar frequently, eat a healthy diet, exercise and try to handle stress with meditation. Yet the insurance companies do everything thing they can to prevent this: they limit the amount of test strips I can get, raise the price of insulin and now are telling me I have to switch to a less expensive insulin that doesn’t work for me.

Our son developed type 1 diabetes, a few years ago, the price of insulin is out of this world, he needs it to live. We pay for our own insurance which is another story but we don’t have prescription coverage. So the insulin is very costly.

My story isn't so much on the actual price of Humira, which is well covered by my insurance, but the bloodwork that has to be done is not covered because of being considered experimental by the insurance company. The bloodwork is expensive.

Oregon Drug Price Transparency Program

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I have neuropathy in my feet. The medical patches and the medicine went to such a high price level a couple of years ago that I had to find cheaper meds to try and help me sleep. I had to drop the pads for my feet. Often the medicine doesn't work as well so that I still sleep with pain. It is hard to deal with this price hike since I know there is a couple of meds out there that can help with my night pain. Not having a full night of sleep is very exhausting and it takes away your energy the next day.
I take a drug that I must take in order to continue to live. It is a brand name drug with no generic equivalent. It is a very expensive drug - without insurance co-pay, price is $2,000 a month. I am concerned that I will not be able to get this drug because I cannot afford it if insurance decides not to cover it.
My husband has PAH and the prescriptions are over $100,000.00 per year. That is more than our yearly income and if it weren't for charitable help with the co-pay he would not be able to take the necessary medicine to keep him alive.
Vaginal cream is over $200 a tube, that is preposterous. It probably costs $2 to make. No transparency, they won't tell you how much it costs to make! Pulmicort inhaler also about $180 for one inhaler. This is also preposterous. I don't use a lot of medications, but my deductible is still about $450!!!!
Aside from being on a monthly prescription my only story is that I am over concerned with knee jerk, over reaction by regulatory bodies who may be sending surveys out to simply stack the deck in their favor. I want to make sure both sides of the story are not only heard but also analyzed objectively in the long term best interest of all those involved.