

Senate Aging Committee

The Complex Web of Prescription Drug Prices, Part I: Patients Struggling with Rising Costs

March 6, 2019

9:30 AM, 138 Dirksen

Purpose

The purpose of the hearing was to discuss the high cost of prescription drugs and hear personal stories from people affected by high drug costs.

Members Present

Chairman Collins, Ranking Member Casey, Senators Rubio, Scott, Hawley, Young, Jones, Braun, Rosen, Hawley, Sinema and Gillibrand.

Witnesses

Ms. Michelle Dehetre, patient advocate

Ms. Pamela Holt, patient advocate

Ms. Donnette Smith, patient advocate

Mr. Sheldon Armus, patient advocate

Ms. Barbara Cisek, patient advocate

Opening Statements

Chairman Collins said these hearings build on the work from 2015 to encourage more competition from generic drugs and to prohibit gag clauses that prevent pharmacists from informing patients about the least expensive way to purchase their prescriptions. It is evident that more work needs to be done. 90 percent of seniors take prescription drugs regularly. One out of four Americans has difficulty affording medicine. People are at a loss as to why the drug prices continue to rise to the point of unaffordability. Prescription drugs don't work for those who cannot take them. On a national level, there is an enormous amount of spending, while millions of Americans cannot afford the treatments they need. Americans are expected to spend \$360 billion, with \$49 billion out-of-pocket, and the federal government picking up another \$163 billion out-of-pocket, in payments to Medicare and Medicaid and other programs. Americans cash-in retirement accounts, work three to four jobs at retirement age, and choose medicine over food. The complexity in the current system seems designed to benefit everyone but the patient. Companies who take the risk to develop these drugs should see a fair return on their investment, but it is important that prices are more transparent and more affordable for key drugs.

Ranking Member Casey said that one of the main topics that comes up in his state is how to make ends meet. There has been unacceptably slow growth in wages over the last four decades, with the cost of living continuing to rise. The cost of prescription medications is at the top of the list of rising costs, and it is busting the budgets of families across Pennsylvania. Just last week, the Senate Finance committee heard from the companies that manufacture and set prices. None of the executives had difficulty making ends meet due to the cost of the drugs they manufacture. They should hear the stories of the parents and seniors and families who struggle to pay for prescriptions. The prescription drug prices are unsustainable. For families to have the money for childcare and retirement and everything

in between, action must be taken on this issue. Common sense policy must be advanced for Americans to afford the medication they need.

Testimony

Ms. Dehetre said that she was diagnosed with type 1 diabetes as a freshman in high school. She is a mother of five with four grandchildren. Diabetes threatens her life. On Friday, she was sent to the emergency room for a low blood sugar crisis. This is not an unusual occurrence since she cannot afford the insulin she needs. She takes Lantus and Humalog. She pays nearly \$300 out-of-pocket per month for the insulin, test strips and needles. She cannot afford another medical bill on top of the \$600 EMS bill and the \$200 ER bill. She takes Humulin N and R, but her blood sugar levels have become more and more unpredictable and the older insulin does not work well. The brand her insurance covers costs \$99, but she was able to get a brand from Walmart for \$55 a month without using her insurance. She needs to test six times a day. Her doctor says she needs a continuous glucose monitor and a pump, but the cost of the pump went up to \$1650 for a three month supply after change to her insurance. She could no longer afford that and relies on syringes and test strips. Spending at least \$300 a month for her diabetes is a major financial strain. She sometimes falls short at the end of the month. Over time, the complications from not properly monitoring insulin can lead to blindness, neuropathy and even death. She wants insurance companies and pharmaceutical companies to wake up.

Ms. Holt said that she was diagnosed with multiple myeloma three months ago. Multiple myeloma is an incurable but treatable blood cancer. She underwent a bone marrow transplant and chemo therapy. She is currently in remission, but to keep it at bay, she must take the treatment Revlimid. For Medicare Part D, she pays \$496 the first month and \$640 every 28 days for the rest of the year. After just one year, she found herself in debt and had to refinance her home. She received a grant from HealthWell for the cost of Revlimid, but the money is not a given. HealthWell may run out of funds. She does not feel that she should be dependent on a grant. Congressional action must bring down drug prices. One solution would be the CREATES Act. There are no competing drugs for the drug she needs to take, so Celgene can charge whatever they want. This year it's up to \$740. She is hopeful that the members of the Committee will sign on to the legislation and will take meaningful steps to pass it.

Ms. Smith said that she has suffered from heart-related conditions from birth. She was born with a heart defect that leads to heart failure. Just after her 40th birthday, she had heart surgery to repair a failing heart valve. After the fourth surgery in 2009, she tried every heart drug. When Repatha became available, her cardiologist tried unsuccessfully to cover it with insurance. Without insurance it would have cost over \$14,000 per year. The applications and appeals process were extremely time consuming for her doctor and his staff. Her insurance eventually approved three months of coverage and the drug dramatically changed the quality of her life. The drug is very expensive, and with insurance, her copay was \$583 per month. She was fortunate enough to discover a manufacturer copay card which sharply reduced the cost. Unfortunately, after three months, the

insurance required her to reapply for coverage. She makes the samples of Repatha stretch out by taking the least amount possible, which concerns her about the effects on her health.

Mr. Armus said that he worked as a pharmaceutical sales rep for many years and managed several companies that manufacture devices. He owns his own medical device company. One month into retirement, he underwent a quadruple bypass surgery. But the surgery and diabetes left him taking seven drugs each day. Xarelto prevents dangerous blood clots; it is a new and expensive drug with a list price of more than \$450 for a thirty-day supply, or one tablet per day. Janssen Pharmaceuticals makes Xarelto, and they have promised to start disclosing the list price on their ads, which is more information than Janssen would like doctors to know. There isn't a generic on the market for Xarelto. He is on Medicare Part D where he only pays a portion of the price, but it is still too much. He fears the month his out-of-pocket price will spike. He never knows when he will hit the donut hole threshold. The deductible for the premiums for Part D is over \$1000 before even filling the first prescription. The donut hole will be closed for patients but it won't solve the problem of prescription drug pricing. The list price of insulin, which has been around for 100 years, has skyrocketed. Patients and taxpayers pay for a percentage of the list price. Therefore, it's in the best interest of the pharmaceutical industries to artificially inflate the list price. According to the Washington Post, 9 out of 10 drug companies spend more on marketing and promotion than they do on research and development. As a patient, he is no longer proud to have worked for the pharmaceutical industry. The issue starts at the top with the high list prices set by drug companies and it ends with patients trying to continue their lives.

Ms. Cisek said that she has two sons, David and Michael, and four grandchildren. She cared for her mother while battling ovarian cancer. She pays \$500 out-of-pocket for medicine and over-the-counter items every month. If she took all the medications her doctors prescribe, the cost would total over \$1500 per month. That's on top of her Medicare, which is \$134, and her Medicare Advantage, which is \$293 per month. She was diagnosed a year and a half ago with diabetes. She lives with chronic pain and needs to get a total shoulder replacement in the next few months. She uses an oxygen concentrator and will need to use portable oxygen tanks. With ovarian cancer in the family, she also needs to get tested regularly. She never knows what insurance will cost from one year to the next and what the prescription drugs will cost. The Imitrex for her migraines cost \$150 before it became generic. Now that it is generic, her insurance will not cover it, and she pays \$49 for 27 pills. Elavil, a medicine that helps with her migraines, is no longer covered and she has to pay out-of-pocket. She spends \$100 on a two-ounce rash cream that insurance will not cover, using the tiniest amount to make it last. Insurance does not cover the shingles vaccine, which will cost \$400 out-of-pocket. The most expensive drug she takes is Nexium, and insurance will not cover it. She has to go through a process every year where her doctor has to send a letter to the insurance company confirming that she must have the brand name drug. She pays \$300 for a 90 day supply. She wants to be able to afford her medicines, but drug prices keep rising and her insurance keeps covering less.

Questions and Answers

Chairman Collins noted that the witnesses are coping with anxiety and uncertainty over what their prescription drugs will cost month-to-month. She asked the witnesses if they understand what they'll be faced with when they get to the pharmaceutical counter and why they're paying what they're paying. **Ms. Dehetre** said she has asked the pharmacy why the price of her prescription has changed and was told it's because her insurance has stopped covering it. **Ms. Holt** said that she typically paid \$46 for a three month supply for an anti-nausea drug, but it was over \$500 the last time she tried to pick it up. She had to go back and pick it up despite the rise in price. **Ms. Smith** said that she takes 12 different drugs, so her problem with Repatha being so expensive was nothing when it was all added together. One woman told her that she had to choose between groceries and her medications. **Mr. Armus** said that he takes a new anticoagulant and has no idea what it will cost. He feels that the situation that has been getting out of control for the past 15 years. He says there must be a bipartisan effort to fix the excruciating pain that patients experience for drug costs. **Ms. Cisek** said that she is frustrated that health insurance plans seem to change the copays so frequently. Pharmaceutical companies are worried about the cost of research, but they are not concerned with the cost incurred to patients.

Ranking Member Casey said that he is grateful for the patients' testimony and noted the urgency to take action. He asked the witnesses if they believe Medicare should be able to use its purchasing power to negotiate drug prices. **Ms. Dehetre** did not understand the question. **Ms. Holt** said yes. **Ms. Smith** said yes. **Mr. Armus** said yes. **Ms. Cisek** said yes. **Ranking Member Casey** asked the witnesses if they believe the US should be able to safely import medications from other countries where they are more affordable, like Canada. **All the witnesses** said yes. **Ranking Member Casey** said he hopes Congress can act upon the recommendations heard from the witnesses. One bill he is interested in is Sen. Stabenow's bill to allow Medicare to negotiate for lower prices. He has another bill on drug importation with Sen. Sanders to allow for the safe importation of prescription drugs from Canada and maybe other countries down the road.

Sen. Braun said that the industry has done a poor job at providing a product and a value-added service. 30 other nations have a better ranking of cost and quality. The system is opaque and confusing, making it hard to participate. Rebates to PBMs are part of the problem, as is drug companies preventing generics from coming to market. He asked the witnesses if they would engage as consumers if there was information to shop around for prices. **Ms. Holt** said she would do quite a bit of phone shopping. **Mr. Armus** said the time has come for prices to be fixed. The list prices will only go sky higher; insurance is structured to increase the prices.

Sen. Jones asked Ms. Holt what the insurance company told her when they denied her coverage and only approved her medication for three months. **Ms. Holt** said the company did not give her a reason. She did not know that the approval was only for three months. **Sen. Jones** asked what she did during the two-year period for preauthorization. **Ms. Holt** said she could not take a statin since the side effects almost made her immobile. She was without any protection for extremely high cholesterol, so she would send in appeals over and over. Finally a physician decided to help her by shaming the insurance companies. Once the three months were over, she was back in the appeals process. She is now getting samples from her doctor. Instead of two injections per month, she is only getting one every one or two months. The appeals process has gone on for

three years. **Sen. Jones** asked what she tells patients when they face this hurdle while managing healthcare. **Ms. Holt** encourages patients to be their own advocate and to not give up.

Sen. Scott asked Ms. Dehetre how frequently she has been in the hospital. **Ms. Dehetre** said that she would be in the ER three to four times a month if she went with the ambulance. She said that her pump supplies are designated as durable medical equipment, so they are not covered. **Sen. Scott** said that it is a foolish economic decision that the insurance company is willing to cover the emergency room visits but not the diabetes supplies. **Sen. Scott** asked if Medicare users are told what drugs are covered and what the copays are. **Ms. Holt** said that they give tiers, but not what the prices are in each category. **Ms. Smith** said that when companies decrease drug prices, the consumer still has to pay for the original price since the drug does not move down a tier. **Sen. Scott** asked what the witnesses would suggest for legislation, such as the CREATES Act. **Ms. Cisek** said that one issue she experiences is pricing transparency and the preauthorization process for name brand drugs, such as Nexium. **Mr. Armus** said that in Florida, pharmacists are required to fill prescriptions with a generic drug if a generic exists. The problem is not knowing what the patient will receive or what they will pay until they go to the pharmacy. They are paying donut hole prices for all drugs until they reach another threshold, which they may not even reach. **Ms. Holt** said that it costs \$1 to manufacture Revlimid, but they charge her over \$740 per pill. Celgene needs to be told that they cannot raise the price of their flagship drug in order to cover their other costs.

Sen. Rosen asked the witnesses how a monthly out-of-pocket cap on prescription drug costs would help. **Ms. Cisek** said that putting a cap on monthly costs would be helpful. **Mr. Armus** said putting a dollar amount, not a percentage, would be helpful, but it must be affordable. **Ms. Smith** agreed. **Ms. Holt** agreed that knowing the cost would be helpful. **Ms. Dehetre** agreed.

Sen. Hawley asked **Mr. Armus** about the difference between how much pharmaceutical companies spend on research and how much they spend on marketing. **Mr. Armus** said that there is a difference between marketing in the industry and other marketing, such as their salesforce. In the 10 to 15 years he was in sales, he never discussed price with doctors, and that was when prices were relatively low. And not once did the doctors ask how much the drugs cost. Doctors still don't know the prices. **Sen. Hawley** said that insurance companies portray themselves as shielding the consumers from the producers driving up the prices. He asked the witnesses if that is an accurate perception. **Ms. Smith** said no, they are not in the business to protect the patient. She cited her experience with the peer-to-peer review process for getting a new drug approved, along with the geographical discrepancies in which drugs get approved. **Sen. Hawley** said that the patients are not doing well while the insurance and drug companies are.

Sen. Sinema asked the witnesses how they bear the burden of managing their medications, insurance coverage and payment assistance options. **Ms. Cisek** said that she took the generic stomach ulcer medication and it landed her in the hospital needing a blood transfusion. She said that a lot of generics don't have the same regulation, with inaccurate milligram counts and different fillers. She misses the insurance that her former husband had, which cost less than her current insurance but had more robust prescription drug coverage. **Ms. Smith** said that she is concerned about the elderly who cannot comprehend the prices of drugs, such as her mother,

who cannot advocate for themselves. **Ms. Holt** said that Revlimid does not have generics. Through manipulation by Celgene, they have kept all generics off the market.

Sen. Gillibrand asked Ms. Holt how needing to refinance her home has affected her children's lives. **Ms. Holt** said that she will not leave her children with an inheritance. She cannot have an income above \$60,000 or else it will make her ineligible for the grant that allows her to afford her current medication. She cannot take vacations. **Sen. Gillibrand** noted Ms. Smith's creativity in rationing her samples from her doctor. She asked **Ms. Smith** what she would have to do if she could no longer receive samples or lost insurance coverage. **Ms. Smith** said she would have to either take statins, which are debilitating, or not take medications at all, and risk a heart attack or stroke. Her Social Security check was cut because she has a civil service pension, and she would not be able to pay for all 12 of her drugs. **Sen. Gillibrand** asked Ms. Dehetre what Congress should do to hold the bad actors, pharmaceutical companies, accountable. **Ms. Dehetre** said that she does not see an end to the price gouging. Until there are changes that the companies are forced to make, she does not anticipate a change to the consumer.

Chairman Collins said that she received a letter from the medical director of diabetes at the Maine Medical Center. Approximately 40 percent of people with Type I diabetes will have a severe low blood sugar reaction over the course of the year, which Ms. Dehetre has experienced. **Ms. Dehetre** said she was able to use the pump for four months until supplies ran out. When she was on the pump, she did not go to the hospital even once. **Chairman Collins** noted that it is ironic that insurers end up paying more money when Ms. Dehetre is hospitalized more often. She asked Ms. Dehetre if her insurance has contacted the company to get the pump approved. **Ms. Dehetre** said yes, but it was to no avail. **Chairman Collins** said that it is so important to hear from patients to shape policy solutions and future proposals. There has been real gaming of the patent system by some pharmaceutical companies. She asked Mr. Armus if the often enormous increase in prices that are tied to changes in packaging or release mechanism are justified, or if they are meant to game the patent system and block generics from entering the patent system. **Mr. Armus** said that manufacturers get 17 years of exclusivity, starting from the moment they start researching, that lets them charge the list price. Manufacturers get tax deductions and credits for research and development but they still charge consumers on the retail end, so they are getting double the value. The TV advertising is totally unnecessary. There may be a necessity to advertise to doctors, but they're advertising to the consumer, who cannot write a prescription. **Chairman Collins** said that she was struck when Amgen, the manufacturer of Repatha, announced in October that they would cut the list price by 60 percent. But that's not necessarily a 60 percent reduction in price for the patient. The startling part of the announcement was that the CEO noted that an estimated 75 percent of Medicare patients prescribed a PCSK9 inhibitor never actually fill the prescription because of the high out-of-pocket cost. Here there is an essential drug but 75 percent of the people can't afford to use it. **Ms. Smith** agreed that people do not fill the prescription when they find out how much the copay is. She spoke of a friend who could not afford the almost \$600 price tag of the prescription.

Ranking Member Casey asked Ms. Smith what she thinks most people need as support to navigate the prescription drug issues for themselves and for their family. **Ms. Smith** said that she had promised her mother she would not end up in a home, but hospice covered medication management and allowed her to maintain her job as a hairdresser. She said that if people could

get their medications at a lesser amount, then people wouldn't have to juggle a full-time job while keeping their family together. More financial help would allow people to provide better care for their families while avoiding nursing homes.

Chairman Collins said that PBMs, insurers, hospitals, healthcare providers and pharmaceutical companies are frequently the witnesses in Congressional hearings, but today the most important people, the patients, shared their stories. It is really important that policy starts from the patients' perspective to try to solve the onerous burden of high and ever rising prescription drug prices. Costs are increasingly a barrier to remaining healthy, getting well and following doctor's orders. No one should have to choose between purchasing prescription drugs and paying the mortgage or grocery bill. No one should go deep into debt or refinance a home to get the drugs needed to stay alive. No one should be cold or hungry to afford prescription drugs. There has been a wake-up call in Congress that is an issue that must be addressed. Innovation in the development of new medicines should not be disrupted, but it is important that patients are being treated fairly and that the system is not gamed. This is a bipartisan cause and many Senators have introduced bills, including Ranking Member Casey's bill to increase the availability of information, and the CREATES bill. Congress's job is not done, so that is why this was the first in a three-part series on the cost of prescription drugs.