

Madame chair, other distinguished members of the committee. My name is Mike Smith. I live in Benton County. My wife and I have four children with bleeding disorders, one with severe hemophilia. We are grateful that we have access to specialty medications that enable them to avoid most bleeding episodes and quickly control those that break through. Those medications enable them and others with bleeding disorders to live normal, active lives.

My family has private health insurance. We plan for and expect to pay our share of medical costs each year, and that includes the \$5000 family out of pocket maximum required by our insurance. Last year we paid \$5000 in medical bills, as we have in years before. Money is tight (we have two kids attending Oregon State), but we pay our fair share without complaint.

Last year our insurance introduced copay accumulators for our specialty medications. I want to tell you my family's story to help you understand that copay accumulators have spawned companies to ensure patients enroll in manufacturer copay assistance programs, exploiting eligible patients and making their lives difficult in the process.

My son with hemophilia takes a specialty medication twice a month that is critical to his living a normal, active life. Without that medication he would experience frequent painful bleeding in his joints. Injuries would lead to emergency room visits, hospitalizations, and might even be life threatening.

We order my son's medication monthly, usually a simple phone call to our pharmacy benefit management company, otherwise known as a PBM. In January 2020, when the copay accumulator was added to our insurance, it became anything but simple. I called our PBM, confirmed the details of the prescription, and arranged the delivery. Later the PBM called back to say that the insurer had declined to cover the medication until I had contacted a company called "SaveOn SP", without explanation who they were. Understand, my PBM tells me that my insurer needs me to call this SaveOn SP -- I'm now dealing with three different companies (none of them the manufacturer) just to get one medication. When I called SaveOn SP, they asked for my son's sensitive personal information. I say "Hold on a minute, why?" and they told me they needed the information to enroll my son in a manufacturer's copay assistance program. That caught me off guard. I needed to talk this through with my wife. She and I called back to SaveOn SP, and this time we spoke to one of their supervisors. Our questioning didn't reveal why it was necessary to enroll in the copay assistance program. In fact, we were told we could opt out of the copay assistance program if we chose. According to our insurance summary of benefits, for specialty medications we had a copay of \$100 for a 30 day supply. We were prepared to pay that, a total of \$1200 over the year, so we declined enrollment in the manufacturer's copay assistance. The next day we got another call from our PBM to inform us that we now owed a copay of \$1250! We argued over the summary of benefits, and got a supervisor involved again. Multiple phone calls, but we never got an explanation why our \$100 copay was jacked up to \$1250. We had a choice: pay the \$1250 each month, quickly reaching our family out of pocket maximum; or, give in and enroll in the manufacturer's copay assistance program. At this point it had been days since that first call to order the specialty medication, and we had run out of time to argue any further. We needed that medication or we'd miss my son's scheduled treatment. We gave in. We gave our consent to enroll in the manufacturer's copay assistance program.

Just one month later, we went through the same ordeal. It was the beginning of February and my son suffered severe stomach bleeding. A visit to his pediatrician in Albany escalated to an ambulance ride up I-5 to Children's hospital in Portland. The doctors put him on a different specialty medication that

controlled the bleeding. It was our third day at Children's, and we were relieved to hear that the doctor was ready to send us home the next morning, but we would need to continue daily treatments of that new specialty medication. This is about 5:00 in the evening and my wife contacted our PBM to order the needed medication, and we hit the same roadblock as a month before. Our PBM could not fill the order until we'd contacted SaveOn SP, but they were gone for the day, "please call back tomorrow". My wife had stayed three sleepless nights at Children's with our son and didn't want to hear that. My son's doctor hears this conversation, politely asks for the phone, and then bluntly tells the PBM that my son didn't need to stay another day in the hospital but he wasn't heading home unless the medication he needed was there waiting for him. Thankfully the PBM released a partial shipment, but held the rest until we were able to contact SaveOn SP and enroll in yet another manufacturer's copay assistance program. Our PBM billed us a \$1250 copay for that partial shipment, again far in excess of the \$100 we owed per our summary of benefits.

That's my story. In the first two months we dealt with copay accumulators, my family twice had to fight for access to the specialty medications critical to my son's health. That medication was denied until we'd done our part for the PBM to gain access to the manufacturer's copay program. And why? Because on top of the \$5,000 we paid out of pocket for medical costs last year, the PBM wanted to get all of the \$15,000 available from each of those programs.

I urge you to pass senate bill 560 for my family and for all the families who live with chronic diseases in Oregon.