

## **Notes for Testimony to Oregon Legislature Committee**

Madame chair, other distinguished members of the committee. My name is Mike Smith and I live in Benton County.

I have a fifteen-year-old son with severe hemophilia. He is a patient of the hemophilia treatment center at OHSU. Up until five years ago, my son experienced painful bleeds in his joints that, even at his young age, left his knees and elbows damaged -- he's already had arthroscopic surgery to clean out his left knee and restore some of the flexibility that he had lost.

Five years ago, my son became a patient of the hemophilia treatment center at OHSU. His doctors prescribed medications that control his hemophilia. Initially it was infusions three times a week that we would give him in the morning before he headed to school, but medications are constantly improving. About three years ago he switched to a simple injection that's only needed once every two weeks. My son is in middle school, he desperately wants to fit in and be like his classmates, and that is what these medications have given him – a normal, active teenage life.

I am grateful for our doctors at OHSU, I am grateful for the medications that give my son a healthy, normal life, and I am grateful for the medical insurance that helps cover the cost of those doctors and medications.

My son's medication is expensive, and my share of those costs is significant. I take advantage of patient assistance when it is available. I understand and support efforts to control rising costs of medications, but I don't understand why a few years ago the pharmacy benefit manager for my insurance suddenly stopped counting patient assistance toward my deductible and out of pocket cost. How was taking away that assistance and taking more money out of my pocket improving the cost of medications? I was not electing to use higher cost or name brand medications, I had no lower cost alternatives, I was providing my son the unique medication he needed to live a normal, healthy life. Why did I find myself on the losing end of a dispute between a pharmacy benefit manager and the manufacturer of my son's medication?

Ironically my pharmacy benefit manager was pushing me to accept the manufacturer's patient assistance. Before the pharmacy benefit manager would authorize the medication, they had me contact a firm called SaveOn SP.

The person on the other end of the phone at SaveOn SP was there to ensure my son was enrolled in the manufacturer's patient assistance program. If I declined, my copayment for my son's medication rose to \$1250 per month, not the \$100 per month stated in my explanation of benefits. I realized that twelve months of \$1250 per month equaled the maximum patient assistance available each year from the manufacturer -- \$15,000 per year. Not a coincidence.

To make matters worse, a month later my son was hospitalized at OHSU with stomach bleeding and severe loss of blood due to bleeding in his stomach. He spent three days in the hospital and was ready for discharge, but needed two weeks of treatment with a different hemophilia medication. We hit the same roadblock with our pharmacy benefit manager, a requirement to contact SaveOn SP to enroll in the manufacturer's patient assistance that was available for that new medication. Problem was, it was after 5:00 here on the West Coast and SaveOn SP is in some time zone to the east and nobody was answering the phone. We were getting nowhere with the pharmacy benefit manager and facing an unnecessary fourth night in the hospital until my son's doctor pled our case to the pharmacy benefit manager

and coaxed them to release an initial supply on the promise that we would complete our call with SaveOn SP the very next morning.

The bottom line is, these medications give my son, and others like him across Oregon a chance at a normal, healthy life. We don't have lower cost or generic alternatives. We appreciate our doctors, our medications, and our insurers and we conscientiously manage our health and minimize our medical costs, but we find ourselves caught in the middle between insurers and manufacturers, with insurers taking more money out of our pockets while complicating if not risking our access to care.

Thank you for your time today – Michael Smith, Benton County, OR