

What Living With von Willebrand Disease Has Taught Me About Profits Taking Priority Over Patient Lives

By Maria Shoemaker

Any person living with a chronic illness knows that we often must become our own advocates in the fight for our health and for fair and accessible treatment and insurance.

As someone with [von Willebrand disease](#), a lifelong bleeding disorder characterized primarily by my blood failing to clot properly or perform as it should due to low levels of von Willebrand factor protein – I've spent years learning the ins and outs of the U.S. health care system, and the battles that patients like me go through to access lifesaving medications on a regular basis.

I was diagnosed with the disorder at age 23 after the birth of my first child due to a lot of bleeding complications. As the mother of five children, I've been concerned about what this disease means for them, and whether I've passed it on. Two of my children have been diagnosed with von Willebrand disease, and we're now waiting for confirmation about the third.

Like many people with chronic illnesses, my medications are expensive. Because I'm a severe type 1 von Willebrand disease patient with an allergy to DDAVP (desmopressin) — a common medication used to treat bleeding disorders — my only option is factor replacement therapy. I switched to a new factor medicine last year called VONVENDI, and each dose is around \$14,000. Most months I use two doses and occasionally a few extras for GI bleeds here and there, but there have also been times after surgeries where I've needed up to three doses per day for a week.

In the past, we were able to count on patient assistance programs to help with our expenses. The patient assistance helped us reach our deductible and helped cover a portion of the copays after. I always expected to pay some of it out-of-pocket, but the assistance helped with a large portion of the cost.

Since my husband switched jobs last year and we're now with a different insurer, our situation has taken a turn for the worse.

I had a bad bleed in January of this year that left me in crisis, but I have not been able to access my factor through my insurance at all this year. According to my new insurer's pharmacy benefit manager (PBM), my factor would no longer be available, and they would not help me pay for it.

The PBM said they could help me if I agreed to participate in a program they manage called SaveOnSP. I was told that the program would find \$20K in patient assistance from the maker of my factor treatment. Then I could get it through their PBM specialty pharmacy, Accredo. The PBM would take all the money from the manufacturer, but it would not apply toward my deductible or out-of-pocket maximums. Historically, they would have only collected roughly \$2K that would have been counted towards my deductible.

If the patient assistance would not count, I would only be able to afford around one month of factor therapy, barring any unforeseen bleeding events. The PBM wanted all the money, but where was my

benefit? I would still be left searching for additional support for my factor, and other medications to manage my bleeding disorder, that my insurance wouldn't provide. Why am I paying them?

Because of that, I've had to forego other health care priorities and procedures, like dental care and a biopsy. I cannot risk suffering another bleed that will put my life in jeopardy and cause me to become even more reliant on a medication that I can't access or afford right now.

There are millions of other people in this country who, like me, are holding out hope that our government will pass legislation that prioritizes fair cost-sharing for patients and requires that payments made by a patient, or on their behalf, count.

The Help Ensure Lower Patient (HELP) Copays Act (S. 1375) being considered right now by the U.S. Senate HELP Committee could have a lifechanging impact on access to medication for me and millions of others who rely on their employer-sponsored insurance.

Pennsylvania state lawmakers are looking at [SB 372](#) to ensure state regulated plans also count all copays. 20 other states have already passed such laws to end harmful copay schemes and bring much-needed cost savings back to vulnerable patients.

The fight is far from over, and I urge fellow chronic disease patients and patient advocates to ask their elected officials to support these bills. I'll continue to share my voice and story like I've always done to advocate for myself and my family. I don't want my children to spend years fighting for funding sources acceptable to insurers in order to access the medications that help them stay healthy and alive.

Unless something changes, there will be too many families out there that will have their lives truly devastated by all this insanity just so greedy PBMs can make an extra dollar.

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