

February 22, 2021

Senator Deb Patterson
Chair, Senate Committee on Health Care
900 Court St. NE, S-215
Salem, OR 97301

Senator Lee Beyer
District 6 - Springfield
900 Court St. NE, S-411
Salem, OR 97301

RE: Support for SB 560

Dear Chair Patterson, Senator Beyer, and members of the Oregon Senate Committee on Health Care,

I am writing as a District 6 resident to urge each of you and the Committee on Health Care to support SB 560 to ensure Oregonian's do not lose access to critical medications or have excess charges for critical treatment not available in generic or other forms. You will have received other communication from various patient advocacy organizations from a variety of afflictions. Rather than restate the basics, I wanted to tell my story.

I have Christmas Disease, also known as Hemophilia B. My blood has less than 2.5% of normal levels of clotting factor IX that yours does. When a blood vessel or artery is compromised (cuts or bruises) a coagulation cascade is triggered to develop fibrin, which forms a natural band-aid that forms a blood clot. Many coagulation factors in the cascade contribute to the production of fibrin, and there is a loop in the process that rapidly accelerates the process. One Factor IX molecule turns into 1000 thrombin, but when those thrombin go through the loop in my blood they find 97 fewer Factor IX molecules for me than for you. That leaves me with 97,000 times less fibrin to stop clotting for each cycle. And there are lots of cycles. So, you can think of it as using one of those tiny band-aids as the only protection you get after open heart surgery.

Needless to say, injuries are problematic for people with hemophilia. When we get injured, we need to supplement my blood with artificial clotting factor. Doctors have told me it is a miracle I survived the 80's and 90's when clotting factor was derived from human blood. Many hemophiliacs died from AIDS contracted from clotting factors that I too received. Today, we use recombinant clotting factors derived from hamster ovaries. So, we are unlikely to contract lethal diseases and we can self-administer an injection to bring our clotting factors to normal levels.

Fortunately, hemophilia is rare but clotting factors are very expensive. Not long ago a puppy ran under my feet and I tripped and fell, landing on my knee and getting a minor abrasion. Even so, I elevated my leg and packed it in ice. Unfortunately, a slow bruise just got worse inside. Two days later I awoke to a very swollen leg with bad bruising behind my knee. I called at 8:00 AM to schedule an appointment with a local hematologist but was told at 4:00 PM to go to the emergency room. The ER doctor looked at my swollen knee and bruising called hematologist for a consult and told the ER doctor to ask what I thought about it and how I was treated in the past. The two of them left it up to the pharmacist to establish the dosing for the clotting factor.

The pharmacist didn't know how to administer the factor and it took around 7 hours in the ER. The next day the hematologist scheduled a late afternoon appointment and then doctor called urging me to rush in or miss my second day of Factor because he didn't know what time the infusion center was closing. After a few days of treatment, my leg felt better but was not fully healed. Just like the first time, it broke

open (internally) and started bleeding again. This time the bruising was from mid-way up my thigh to my foot (nearly black with purple at the edges).

Fortunately, I learned about the hematology center at OHSU, one of seven regional hematology centers in the U.S. I had to be driven from Eugene, to Portland, but they really understood my condition. Most hematologists are oncologists with some extra study of blood. They see few hemophilia patients and rarely understand current hemophilia treatment. My specialist informed me I should be receiving half the Factor IX needed to bring me to normal levels and have a chance at normal healing. Back to the prior example, the oncologist/hematologist gave me a medium sized band-aid, but it wasn't big enough for the injury and it wasn't administered long enough to let the damage heal.

Great, now I have a doctor that understands my condition, knows how to treat it and treatment is available that isn't likely to kill me, but it's expensive. My little puppy triggered over \$500,000 in clotting factor. It would have been much less if properly prescribed from the beginning. It also cost tens of thousands for infusion center administration of the clotting factor, and tens of thousands for the ER, all as required by my insurance company. Eventually, the hemophilia center sent a nurse to train me to do it myself.

So here is why I am telling you this long story. Insurance companies are arguing that patients need skin in the game to control the cost of health care. But I couldn't once get an estimate of the costs for services or prescriptions in advance. Going to the ER the first time for a banged knee would have been laughable, had I had clotting factor on hand to self-administer as I do now. Since then, having clotting factor on hand has saved the insurance companies tens of thousands of dollars each time I needed treatment. I call the hemophilia center at OHSU, show them the injury with video call and get instructions on how much clotting factor to infuse.

I am self-employed and I have marketplace insurance that allows for a Health Savings Account (HSA). On those plans I have to pay my monthly premiums (over \$1400/month for my wife and I) plus 100% of my deductible/co-pay and 100% of my out-of-pocket limit before the insurance company pays a dime for my care. The out-of-pocket limit is \$7,000 per person. So, I will likely pay \$23,800 this year plus whatever part of \$7,000 that my wife's care requires. That could be \$30,000 per year for healthcare. If I had coverage without the HSA, the deductible would be a percentage and the insurance would start paying sooner, but with my treatment costs I would still reach out-of-pocket limits each year and monthly premiums would be considerably higher.

Only 3 years ago, my insurance company allowed pharmaceutical co-pay assistance programs to apply to patients' deductibles and out-of-pocket limits. That is what the programs were designed for. But now, every insurance company in the marketplace insurance plans and many employer plans, are taking the co-pay assistance funds from the pharmaceutical companies without crediting the funds to the patient's co-pay or out-of-pocket limits. The pharmaceutical companies generally have co-pay assistance for my treatment of between \$12,000 to \$20,000 per year. The insurance companies take that money and still require patients to make co-payments on other treatment. With the cost of clotting factor, one injury requires my full out-of-pocket expense each year.

My wife has been out of work because of COVID but I have been fortunate to keep working from home. Apparently, by depriving me of the \$7,000 co-pay assistance, insurance companies don't just get my \$7,000 from the assistance program and from me, but they leverage it into \$19,000-\$27,000. It seems

like perpetrating a fraud on the pharmaceutical companies. As I understand it, the insurance reports my co-pay obligation of \$7,000 to the pharmaceutical company to get the first payment. On the next prescription, because they didn't credit that money to my co-pay account, they report that I still owe \$7,000 in co-pay and collect again, and again. When the co-pay assistance runs out, they bill me for another \$7,000.

In 2018, I saved my insurance company over \$9,000 by catching a billing error. Without even a thank you, they told me I should get another insurance plan because the following year they would not be crediting the co-pay assistance to my co-pay obligations. I felt like they were telling me that my preexisting medical condition cost them too much money, so they wanted me to find another insurer.

Bottom line is that patients are the only ones with skin in the game, it is our lives that are on the line, not the insurance companies'. My insurance has gone up by more than 10% every year (some more than 20%) for the past 10 years and deductibles, co-pays, and out-of-pocket limits have more than doubled in that time. Meanwhile out of network care is now non-existent except for emergencies and they are taking pharmaceutical assistance from patients when profits are at all time highs. Our system of health care is broken in more ways than this. SB 560 won't fix the bigger problem, but it will help Oregonians that are struggling to make ends meet after COVID to keep the assistance that pharmaceutical companies intended to benefit patients.

Please, don't let insurance companies abuse patients. We cannot control the costs, they have the bargaining power, we have none. We are paying more than ever, receiving less care than ever, and getting abused in the process.

You can help by supporting SB 560 and telling your colleagues why they need to do the same.

Thank you,



David Shirk
4383 N Shasta Loop
Eugene, OR 97405

541-954-8177