

My name is Susan Nolte, and I'm writing in support of SB 404.

In 2022, after months of searching for an explanation to my symptoms, I was diagnosed with pancreatic cancer and was told that I'd need chemotherapy. Despite being insured through my husband's employer, getting my prescribed chemotherapy medications was extremely difficult as my insurance company would not pay for meds through the OHSU pharmacy, and instead insisted I get them through an online specialty pharmacy, Accredo. My other option, a local Walgreens pharmacy, did not handle chemotherapeutic drugs.

Communication with that online pharmacy proved near impossible. Often I would be handed off to 3-4 different people, repeating my reason for calling and repeating my personal information each time. There were significant delivery issues with our address, and I was concerned that my expensive medication would be delivered to the wrong address, sit out in the summer sun for hours without my knowing, or the delivery person wouldn't be able to find our house at all (a frequent occurrence).

I literally spent hours on the phone trying to solve these issues. Out of a 2 week period, I called almost every business day or received calls sometimes during inconvenient moments but I was fearful if I didn't answer it might make matters worse. From July 5th to July 11th last year, I made at least a dozen calls totalling more than 6 hrs of phone time. Luckily I am retired, because there is absolutely no way I could have managed the communication effort if I had still been at a full-time job.

Finally, the anxiety from waiting to start my treatment became too much, so I decided to pay for the first round of my prescriptions out of pocket, with some financial help from family members. Once I told Accredo that I was going to pay for the prescriptions out of pocket, they refused to tell me how much it would cost. I abandoned that effort and purchased the first round of drugs locally at OHSU. However, even after beginning my chemotherapy, I still had to spend hours on the phone with Accredo trying to resolve the issues for subsequent rounds of treatment. One of my absolutely "don't know whether to laugh or cry" moments was when an Accredo employee asked me how I was doing and I said, "I'm feeling kind of crappy and nauseous today" and she replied absent-mindedly (she was looking something up on her computer), "That's nice".

Eventually I attended an event hosted by my husband's employer pertaining to company benefits. I spoke with a representative from Express Scripts and she eventually arranged a "concierge service" for me so that I only had to speak to one individual every time I needed a refill or had a problem. This proved to be very effective, but came after weeks of frustration and delaying care for my cancer.

I was lucky enough to be able to spend the time necessary to figure this out, and to have family members who could help me afford my medication, but I know that many people would not be able to do the same in my situation. If I had not been able to do that, it would have delayed the start of my treatment even more and may have had a significant negative impact on my long term prognosis. I was lucky that the side effects of my chemotherapy were tolerable AND I am comfortable with technology AND I am very, very persistent (annoyingly so). I was lucky. Another patient in my position without my time, persistence and financial resources would have been in trouble.

My experience led me to wonder what happens for other patients in similar situations without my resources. I had heard that there are supposed to be financial assistance programs

available for indigent patients and out of curiosity, I called to see if this was true. A very annoyed sounding man told me curtly that the coffers were empty and that there was a long waiting list. I hung up and counted my blessings.

For people who cannot pay for expensive medications upfront; for people who cannot afford the time and effort required to navigate our broken system; for people without access to an employer who helped resolve my issues; for people who are not as lucky as I was: We need lower cost prescriptions, and a system which works to deliver critical medications to the patients who need them. For all these reasons, I urge you to support legislation that lowers prescription drug costs and that protects patients navigating the prescription drug system, including SB 404.