Chairman Vickrey:

My experience with a specialty pharmacy...

I started trying to get on a prescription in late 2019 to help with a condition I've had for 25 years. I was told that my insurance approved the medicine, and that I would have to coordinate with a specialty pharmacy (Alliance RX Walgreens Pharmacy) to get the meds. I was told by my dr's office that the pharmacy would be calling me to set up my first delivery, but no call came. Finally, I called Alliance to get the ball rolling. I was on the phone with them for 34 minutes this first call, but I thought maybe that was just because I was starting a new drug. I had used Walgreens pharmacy probably 15 years ago, so my patient data was in their system, but was not updated. They asked all kinds of questions about the symptoms I was experiencing, how the symptoms affected my life, etc. I found this to be fairly inappropriate. There is no reason that my pharmacy should need to know anything about this – my dr. ordered the meds and my insurance approved it...SEND ME THE MEDS. So, at the end of the call, we worked to schedule the delivery. The medicine must be kept refrigerated, so they told me I couldn't have it delivered unless I would be home to put in the fridge and that they can't ship on Saturday for Monday delivery because it can't sit for a day. I picked a day in the middle of the week – with no regard to getting the medicine as soon as possible, which would have been the priority had I been allowed to use my regular pharmacy. On the scheduled date, I received nothing. I also had received no email or call telling me that it was or wasn't going to ship, so I was frustrated by the whole thing. I called them. I spent another 30 minutes talking to them and they told me that they weren't sure that I had all of the approvals I needed. After verifying that I did, indeed, have all of those in place, I had to answer all of the invasive questions again. I still don't think it's any business of the pharmacy's as to my symptoms, etc.

I received the shipment. It was packed in an insulated cooler with ice packs in a huge box, while the meds were only 2 small syringes. Seemed incredibly wasteful.

The way this medicine works is that it requires a loading dose. I was to use the med (both syringes) at the start of week 0 and another dose of 2 syringes on week 4. Toward the end of week 3, the pharmacy called me to set up the next delivery. I was really excited that I didn't have to initiate it. When I talked to the lady, however, I had to go back through all of the invasive questions again, plus a bunch more about the side effects I'd experienced, the results I had had so far, etc. Again, THIS IS NOT THE BUSINESS OF MY PHARMACY. If they want information for the manufacturer, just ask me to fill something out. I will do that, but I don't feel it is appropriate to share this information with the random lady from the pharmacy. The call took 38 minutes. I was set for my script to arrive on 2/6. Or so I thought. On 2/6, it did not come. On 2/7, it did not come. On 2/8 it didn't come. Again, I received no notification about it shipping or not shipping, so I was confused and mad. I called the pharmacy on Saturday, but they only had emergency help available on Saturday (quite convenient). Monday I called to find out why I didn't have it. The man I spoke to said that it had been pulled from the truck because my insurance refused to authorize it. WHAT?? I told him – I have a letter at my house from the insurance company authorizing this medication. He told me to go find it and call back. So I raced to my house (the injections were due to be administered on Tuesday) and found the letter. I called back and got the insurance coordinator at the pharmacy, who was not only unhelpful, but also incredibly rude. She told me that I wasn't being sent the medicine because it hadn't been 90 days since my last dose. I tried to explain the loading dose and such, but she said there was nothing she could do. I called my insurance company and got a lovely human who looked into my issue. She said the problem had

nothing to do with the insurance company. The insurance company actually issued two preauthorizations — one for the loading dose and one for the regular 12 week dosing. She said the pharmacy wasn't looking at the correct one. I suggested that I would just call the pharmacy but she said she would really like to do it herself because she was so upset for me. I was placed on hold while she called and told them that they had the proper approval all along. That call was another 45 minutes of my life wasted. She came back on the line and said that they had told her they were planning to ship it that day, but that she told them that she had no reason to believe that they actually would. She stayed on the line with them until they were able to give her a confirmation number. Then, when she came back to me, she told that they actually (the pharmacy) had a website where you can track the shipments. I had no idea about that. I set up a log in and of course, when I looked at the status, there was an error. Nice.

Also, after receiving and administering 2 doses, I still don't know what this will cost me. They said it will take several months for it to process and for them to know the final cost to me. I find this absurd. What if I can't afford it?

In summary, I FULLY SUPPORT HB 2598.

Kristen Pettey

Winfield, Kansas