

HB 1216 – Senate Human Services Committee – March 10, 2025

For the record, my name is Rep. Karen Karls. I represent District 35 in central Bismarck.

My husband Ken was executive director of the Cystic Fibrosis Association of ND for many years. 2 ½ years ago I visited with Karen, an adult with cystic fibrosis, a hereditary, chronic disease. She told me how the miracle drug Trikafta has changed her life, but it's very expensive. She has good insurance, but the deductible is \$5,000. This medication is \$28,000 per month. Once she meets her deductible she is covered for the rest of the year. The drug company gave her financial assistance in the form of a \$5,000 VISA card to help her afford her medication. The card was accepted, but she was later billed for the entire \$5,000 because the insurer no longer counts payment by a 3rd party toward her deductible. She is here today to share her testimony and will explain in more detail. (Please note there are submitted testimonies online from people suffering from other rare diseases.)

Needless to say, medications used to treat chronic diseases like CF, hemophilia and others are extremely expensive. Why? Because the pharmaceutical company that takes on the research for this disease faces YEARS of lab testing, clinical research, and then faces the rigors of winning FDA approval. There is a comparatively small market for these medications, even though they are "miracle" drugs—there are no generic alternatives for them! Thus the extremely high costs.

To help patients better afford their medications (and stay on them) many 3rd-party entities, including the drug manufacturers, offer cost-sharing assistance. Historically, commercial health insurance plans have counted this assistance towards a patient's deductible and maximum out-of-pocket limit, providing relief from high cost sharing and making it easier for patients to get their medications.

Unfortunately, health insurance carriers have adopted policies, often referred to as "accumulator adjustment programs" (AKA "copay accumulators") that block manufacturer assistance from counting towards deductibles and out-of-pocket limits. This means patients could be paying thousands more at the pharmacy. Many have relied on this assistance and have no idea that their health insurer no longer counts it toward their cost-sharing obligation. This can result in unpleasant surprises at the pharmacy counter where they may face thousands of dollars of unexpected costs.

If companies are willing to create a miracle drug and help patients obtain it via drug assistance programs, these should be accessible to them. We need to update our laws to prohibit insurers from this practice and enable patients to access and afford the lifesaving medications they need to manage their chronic illness. HB 1216 hopes to accomplish this.

Madam Chair and member of the committee, I will walk you through the bill, if you like.

Section 1 is the definition section; things to note...this bill is for prescription drugs only, specifically drugs for which there is no generic equivalent. The “meat” of Subsection 2 is on page 2, line 1 & 2: “...the health benefit plan provides for the inclusion of any amount paid by the enrollee or paid on behalf of the enrollee by another person.” Section 2 deals with self-insurance plans; LC informed me that if our state PERS plan ever becomes self-insured, we will need these provisions.

I will stand for questions.