

HB 1413 - Senate Human Services Committee - March 20, 2023

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.

Recently I visited with Karen, an adult with cystic fibrosis, a hereditary, chronic, fatal disease. She is here today to share her testimony. I will attempt to explain the problem she has run into recently. (Please note: there is submitted testimony from the Blood Disorders Alliance of ND with a similar story.)

Needless to say, medications used to treat chronic diseases like CF and hemophilia 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 very 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 such as discount coupons (AKA "copay assistance".) Historically, commercial health insurance plans have counted these coupons 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 coupons 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 these coupons. 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 continuing this practice and enable patients to access and afford the lifesaving medications they need to manage their chronic illness. HB 1413 hopes to accomplish this.

After reading and studying this bill, I have a proposed amendment to clarify that this deals only with the prescription drug part NOT the health care services side which the original bill dealt with. Subsection 3 covers the ERESA concerns we heard after the hearing in the House committee. I provided you all a paper copy of the proposed amendment plus the "Christmas Tree" version of the amended bill for your convenience.

Madam Chair and member of the committee, I will stand for questions.