

HB 1413  
House Industry, Business & Labor Committee  
January 25, 2023  
Testimony of Rep. Karen Karls, District 35, Bismarck

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 many years.

Recently, I visited with Karen, an adult with Cystic Fibrosis, a hereditary, chronic, fatal disease. People with CF typically have frequent lung infections and require hospitalization an average of a week, 2 times per year to receive concentrated IV antibiotics and medicated breathing treatments.

Within recent years, amazing progress has been made by Vertex attacking the source of the disease in the mutated chromosome that causes cystic fibrosis. Karen now takes Trikafta a 3-drug combo. She no longer requires a twice a year tune-up and recently her nebulizer treatments were discontinued.

The problem with miracle medications like Trikafta is that they are very expensive to develop and to receive as a patient. Her monthly dose costs \$25,000. Her healthcare insurance covers \$20,000, but requires an annual \$5,000 out-of-pocket maximum. She does not receive the kind of wage to afford this. To help her out, Vertex issued her a \$5,000 VISA gift card which she used to cover that \$5,000 cost. However, her insurance company refused to apply it against her out-of-pocket expense and requires her to pay it. Most people who hear the story wonder why the insurance company would care about a 3rd-party paying her out-of-pocket maximum.

Karen heard about a plan in Virginia seeking to remedy this Catch 22 situation. I brought the concept to the Legislative Council. The bill before you mimics that Virginia plan. There is one word however, that we missed and it gave the PERS folks major heartburn. I have an amendment for P. 1, line 10: after the word coinsurance, delete the word “copayment” and the comma before it. A group representing pharmaceutical companies requested another amendment. (23.0392.01002) and I included a copy of both amendments.

The intent of this bill is not to eliminate co-payments, but to allow a third-party to assist with the out-of-pocket maximums...to help people who suffer from chronic diseases. Thank you Mr. Chairman and members of the committee.

PROPOSED AMENDMENTS TO HOUSE BILL NO. 1413

Page 1, after line 22, insert:

- "3. If application of this section would result in health savings account ineligibility under section 223 of the Internal Revenue Code [26 U.S.C. 223], this section applies to health savings account-qualified high-deductible health plans with respect to the deductible of the plan after the enrollee has satisfied the minimum deductible under section 223, except for an item or service that is preventative care pursuant to section 223(c)(2)(C), in which case this section applies regardless of whether the minimum deductible under section 223 has been satisfied."

Renumber accordingly

23.0392.01001  
Title.

Prepared by the Legislative Council staff for  
Representative Karls  
January 20, 2023

PROPOSED AMENDMENTS TO HOUSE BILL NO. 1413

Page 1, line 10, remove ". copayment."

Renumber accordingly