

HB 1413

Senate Human Services Committee

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Insurance practice hurts access to life-saving medicines

DAVINEY MCKAY-GOLDEN VALLEY, ND

I live with a deadly chronic disease called Cystic Fibrosis. Thankfully, I also live a full life, because I take medications that keep my lungs healthy. Without all these medications, patients like me would have a completely different life. My medication and treatment plan allows me to live my life to the fullest, play sports, and plan for a jam-packed future.

It was heartbreaking to learn that recently, health insurers and pharmacy benefit managers (PBMs) are classifying medicines like the ones that have saved my life as “non-essential health benefits.” Calling the medicines “non-essential” has allowed these companies to find loopholes that allow them to make a profit off of money intended to help patients afford these life-saving medicines. By deeming life-saving medicines as “non-essential,” PBMs have changed a rule that no longer counts patient assistance toward their customer’s annual out-of-pocket maximum. This means the insurance companies keep collecting the money from pharmaceutical manufacturers or charities (intended to benefit patients) until it runs out, and then they force patients to pay thousands more to reach their out-of-pocket maximum. Many of my medications come with a hefty co-pay and there have been times that our pharmacy would not fill a prescription knowing the co-pay would break us. My family has also had to refuse prescribed medication because we were unable to afford the co-pay.

For example: If a patient has a \$250 copay for a drug, but is enrolled in an assistance program, this often allows the patient to owe \$50, with the manufacturer paying the remaining \$200. In a traditional insurance plan, the entire \$250 (\$50 from the patient and \$200 from the drug manufacturer) would count toward the patient’s deductible and the maximum annual out-of-pocket cost. With these new loopholes, payments made by a coupon from a manufacturer, or even a charitable organization, are excluded from the deductible and the annual maximum-out-of-pocket cost. The Cystic Fibrosis Foundation — and many others — have done so much for our family, and CF patients across North Dakota would be devastated if we couldn’t accept their charity.

In the example above, the patient’s \$50 payment would count toward the deductible and maximum out-of-pocket cost, even though the total copay amount was \$250. Now, the patient keeps paying over and over, as does the manufacturer, without ever hitting the maximum out-of-pocket cost.

Even worse, most Cystic Fibrosis patients have no idea their plan has an accumulator or maximizer until they get an unexpected bill in the mail, sometimes for thousands of dollars. CF medication can cost \$25,000 per month depending on the medication and the severity of the disease. Insurers and middlemen have hidden these new terms in the fine print of their plan documents, and oftentimes, even insurance experts have a hard time spotting maximizers and accumulators when they review a plan’s paperwork. This is immoral and will hurt CF patients across the nation if we don’t do something about it.

Lawmakers in states across the country have thankfully taken notice. State and federal bills have been introduced to ban this practice and ensure financial assistance meant for patients is applied to their out-of-pocket maximum. These bans would end the practice of using copay maximizers, accumulators or other predatory practices being utilized by insurance companies and PBMs.

We are so grateful that in Bismarck, Representative Karen Karls has introduced House Bill 1413, which would limit out-of-pocket payment obligations under health insurance plans, and enhance the ability for patients across the state to afford their prescriptions. Representative Karls has shared testimony of loved ones who fight with Cystic Fibrosis on the House floor, sharing how many CF patients would be forced to pay thousands of dollars a month out of pocket if they weren’t able to continue to use their coupons from their medication’s manufacturer.

Last year, legislation H.R. 5801 was in Congress. The Help Ensure Lower Patient (HELP) Copays Act had bipartisan support and had more than 60 co-sponsors but unfortunately did not move this past session. We need to try again and encourage members of the North Dakota Delegation to support H.R. 5801 and pass the bill in the new Congress this year. Families across North Dakota need to join to put an end to copay accumulator programs that have harmed our families, friends, and neighbors. Please join our family in supporting House Bill 1413 here in our state and asking our Members of Congress to support the HELP Copays Act.

McKay, of Golden Valley, is a junior at Beulah High School. She was born with Cystic Fibrosis, a chronic disease that

she has learned to embrace and conquer.