March 25, 2022

Dear Chair Stevenson and Committee members,

Thank you for including HF3611 on your Commerce Finance & Policy Committee today.

My name is Jean O’Connell, I’m a Board member of the Hemophilia Foundation of MN/Dakotas. I’m also the sister of 4 siblings who have Hemophilia.

Hemophilia is a rare, genetic bleeding disorder affecting about 20,000 Americans that impairs the ability of blood to clot properly. Without treatment, people with hemophilia bleed internally. This bleeding can lead to severe joint damage, permanent disability, or even death.

Patients depend on prescription medications to treat or avoid painful bleeding episodes. Current treatment and care are highly effective and allow individuals to lead healthy and productive lives. This treatment is extremely expensive, costing anywhere from $250,000-1,000,000 annually. **It's important to understand that these drugs are not available in generic form.**

Many Minnesotans with rare diseases are finding that in addition to fighting their disease they need to fight with their insurance companies about paying for life saving drugs. Accumulator adjuster programs started in 2016 and now appear in up to 80% of commercial health plans.

Co-pay assistance helps patients afford out-of-pocket costs for their medications. Patients are using co-pay assistance to pay for life-saving prescription drugs early in the year. The insurance companies are gladly accepting those payments and then telling Minnesotans that they don’t count toward their out-of-pocket maximums. My father, Bernard Maguire, was an insurance agent in Minnesota for over 25 years, he would be appalled to know this practice is being allowed to hurt Minnesotans

When a family or individual doesn’t have $8-17,000 to pay out-of-pocket costs, they may not receive the medication they need, or skip treatments. This can result in people being unable to stabilize their medical condition and end up in the Emergency Room with an internal bleed that could have been prevented.

This bill would eliminate accumulator adjuster programs in Minnesota. I ask that you move this legislation forward for a vote in 2022.

Sincerely,

Jean O’Connell

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