

HB1413

Senate Human Services Committee

March 20, 2023

Testimony of Karen M Cossette, Bismarck

Good morning Madame Chair and members of the committee. I support HB1413.

Let me quickly tell you about myself. I was born with cystic fibrosis. I was hospitalized the first time for a “tune-up” the summer I was age 16. A “tune-up” is 10 to 14 days of hospitalization with intense IV antibiotic treatment, numerous breathing treatments and chest physiotherapy each day, nutrition support and rest. My next “tune-up” wasn’t until college. Then in 1996, I started needing a “tune-up” every 3 months. This continued for over 20 years. In 2012, a new drug, Orkambi, became available that fixed my cystic fibrosis on a cellular level. My hospitalizations dropped to once every other year or so. As the years have passed, there have been newer drugs that work even better. The current iteration, called Trikafta, is simply a miracle. My last “tune-up” was in March 2019. In September 2022, all of my nebulized medications were removed from my active medications list. I am able to maintain normal lung function without breathing treatments!

As with all new medications, Orkambi was very expensive, \$20,000 per month. However, I have good insurance and the pharmaceutical company, Vertex, has a copay assistance program that covered the initial copay, which for me was \$5,000. Now Trikafta is \$28,000 per month. Vertex still covers the copay, but my insurance has changed and copay assistance programs do not count toward my deductible. In order to fill my medication the first month of the insurance year, I have to come up with \$5,000 to get my medication. I’m lucky in that I also have the support of Cystic Fibrosis Association of North Dakota. CFA of ND reimbursed my \$5,000.

This isn’t just about me and my expensive miracle drug. This applies to any drug that has a copay assistance program. If insurance companies are allowed to do this, our seniors on fixed incomes will face the same problem. They will have to choose whether they can afford the medication or not. As we already know, many will choose to not pay the high copay for the medication.

We pay for insurance so it will cover the expensive things like hospitalizations, ER visits and medications. Now the insurance companies are trying to save money by getting the deductible paid twice.

Thank you for allowing me to tell my story.

Respectfully submitted,

Karen M. Cossette, Bismarck, ND