

HB1216  
Senate Human Services Committee  
March 10, 2025  
Testimony of Karen M Cossette, Bismarck

Good morning Madame Chair and members of the committee. I support HB1216.

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, which I am taking is called Trikafta. For me, it 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 an organization called “Health Well” gives me a grant to cover my copay. Sooner or later, health insurance companies will find a way to work around that as well.

Listening to testimony in January, I heard discussion that I’d pay the \$5,000 deductible throughout the insurance year without the assistance to cover my copay. I agree, I would pay that amount. However, payment plans can be setup with providers apart from pharmacies. In order to get my medication, \$5,000 must be paid. Period.

I also heard that the copay assistance rewards my choice of their drug. Let me be the first to tell you, if a lollipop a day had the same results for me as Trikafta, I’d order a lot of lollipops! I will take the drug that works. My alternative here is to go back to constant coughing, quarterly 2 week hospitalizations, and a grueling schedule of breathing treatments with 3 to 4 different nebulized medications multiple times a day. Most importantly, I’d have to be on disability again.

We pay for insurance so it will cover the expensive things like hospitalizations, ER visits and medications.

Thank you for allowing me to tell my story.

Respectfully submitted,

Karen M. Cossette, Bismarck, ND

**Karen Cossette  
HB1216**

<b>Service date</b>	<b>Provider or facility name</b>	<b>Prescription name</b>	<b>Rx cost</b>	<b>Plan paid</b>	<b>Your share/ Your Cost</b>
12/28/2024	CVS SPECIALTY 02921	TRIKAFTA TAB -	\$ 28,669.68	\$ 28,669.68	\$ -
11/26/2024	CVS SPECIALTY 02921	TRIKAFTA TAB -	\$ 28,669.68	\$ 28,669.68	\$ -
11/01/2024	SANFORD PHARMACY B	TRIKAFTA TAB -	\$ 26,918.65	\$ 26,918.65	\$ -
10/04/2024	SANFORD PHARMACY B	TRIKAFTA TAB -	\$ 25,834.73	\$ 25,834.73	\$ -
09/06/2024	SANFORD PHARMACY B	TRIKAFTA TAB -	\$ 25,834.73	\$ 25,834.73	\$ -
08/13/2024	SANFORD PHARMACY B	TRIKAFTA TAB -	\$ 25,834.73	\$ 25,834.73	\$ -
07/09/2024	SANFORD PHARMACY B	TRIKAFTA TAB -	\$ 25,834.73	\$ 25,834.73	\$ -
06/10/2024	SANFORD PHARMACY B	TRIKAFTA TAB -	\$ 25,834.72	\$ 19,932.68	\$ 5,902.04
05/13/2024	SANFORD PHARMACY B	TRIKAFTA TAB -	\$ 25,834.73	\$ 25,834.73	\$ -
04/18/2024	SANFORD PHARMACY B	TRIKAFTA TAB -	\$ 25,834.73	\$ 25,834.73	\$ -
03/14/2024	SANFORD PHARMACY B	TRIKAFTA TAB -	\$ 25,834.73	\$ 25,834.73	\$ -
02/15/2024	SANFORD PHARMACY B	TRIKAFTA TAB -	\$ 25,834.73	\$ 25,834.73	\$ -
01/17/2024	SANFORD PHARMACY B	TRIKAFTA TAB -	\$ 25,834.73	\$ 25,834.73	\$ -
12/22/2023	SANFORD PHARMACY B	TRIKAFTA TAB -	\$ 24,395.40	\$ 24,395.40	\$ -
11/24/2023	SANFORD PHARMACY B	TRIKAFTA TAB -	\$ 24,395.40	\$ 24,395.40	\$ -
10/25/2023	SANFORD PHARMACY B	TRIKAFTA TAB -	\$ 24,395.40	\$ 24,395.40	\$ -
09/27/2023	SANFORD PHARMACY B	TRIKAFTA TAB -	\$ 24,395.40	\$ 24,395.40	\$ -
09/05/2023	SANFORD PHARMACY B	TRIKAFTA TAB -	\$ 24,395.40	\$ 24,395.40	\$ -
07/31/2023	SANFORD PHARMACY B	TRIKAFTA TAB -	\$ 24,395.40	\$ 24,395.40	\$ -
07/06/2023	SANFORD PHARMACY B	TRIKAFTA TAB -	\$ 24,395.40	\$ 24,395.40	\$ -
06/06/2023	SANFORD PHARMACY B	TRIKAFTA TAB -	\$ 24,395.39	\$ 18,407.20	\$ 5,988.19
05/05/2023	SANFORD PHARMACY B	TRIKAFTA TAB -	\$ 24,395.40	\$ 24,395.40	\$ -
04/06/2023	SANFORD PHARMACY B	TRIKAFTA TAB -	\$ 24,395.40	\$ 24,395.40	\$ -
03/09/2023	SANFORD PHARMACY B	TRIKAFTA TAB -	\$ 25,343.24	\$ 25,343.24	\$ -