Dear Chairwoman Kahle and Esteemed Committee,

My name is Emily Schaller and I am a proud Michigander, thriving with cystic fibrosis(CF). CF is a genetic progressive disease that causes thick and sticky mucus in the lungs which can lead to recurring lung infections and loss of lung function. CF can also affects the digestive system, and much more. When I was diagnosed in 1983 my parents were told I wouldn't live long enough to graduate from high school. On February 21, 2021 I turned 39 and I am happy to say that I have never been healthier in my entire life.

In my teens my health started to decline, with hospitalizations to treat lung infections happening 1-4 times a year. Medications specifically for CF started to come out in the 90's and my daily treatments were now lasting hours. I was also taking about 40 pills a day. All of this to keep me out of the hospital. This cycle lasted into my mid 20's where any glimpse of a future was always overshadowed by the next lung infection and hospitalization. As I watched my life slip away I was too sick to work and was placed on Social Security, Disability and Medicare.

Around 2006 I decided I was "sick of being sick" and wondered if there was something I could do. I started running and biking very slowly to see if exercise would help me. While it did improve my health, I still had classic CF with many ups and downs.

In 2012 things changed for me and the cystic fibrosis community. A groundbreaking medication called Kalydeco was approved by the FDA. Kalydeco targets the underlying cause of CF and has single handedly given me a life that I never dreamed possible.

In the past 5 years I've run three full marathons, several half marathons, and gone on annual 500 mile bike trips. Because of Kalydeco I was deemed "too healthy" to depend on Social Security, Disability and Medicare. Since then I've had to invent a new future and figure out how to live like everyone else. I now work full time at the Rock CF Foundation, the non profit I founded in 2007, and have my own health insurance plan through the "Exchange."

The cost of my CF medications is very high, coming in at roughly $615,000 annually. The copay for my Kalydeco is around $6,950. Thanks to the co pay assistance program provided by the drug manufacturer, my deductible is met first of the year and I don't have to worry about paying a penny for the rest of my medications. This is how it has worked since buying my low premium/high deductible plan in 2015, but not now.

Without notification from Blue Care Network this has changed for 2021. The co pay assistance for my life saving drug is no longer recognized, and now I am now being told I have copays of $12,163, $5,561, $5,645, $4,135 for my other CF medication. The past 2

months have brought me to tears with frustration and anger. I've spent hours daily on the phone with my pharmacy, looking for copay assistance from other drug manufacturers, and even applying for assistance from non profit funds. I should be enjoying the life I never dreamed of, but now I am left with constant stress and the real thoughts of putting off medications and treatments because I still have over $5,000 to reach my deductible and out of pocket costs.

The drug pricing debate is ongoing, this I know, but it should not be taken out on the backs of those living with diseases and conditions which require high cost-life saving medications. Copay accumulator adjuster programs are wrong.

Thank you for your support of HB 4353 and prioritizing the health of Michigan residents.

Sincerely,
Emily A. Schaller
Founder/CEO Rock CF Foundation
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