Statement in Support of HB18-1260

By Dr. Sara Amodio

1. Happy (belated) Rare Disease Day! February 28th was Rare Disease Day. Delighted to be here to speak with you about my experience as a patient with a rare disease and my experiences with the medications used to keep me alive.
2. When we talk about rare or orphan diseases, the term "rare" is somewhat misleading. Collectively, 1 in 10 people have a rare disease. Chances are you know someone with a rare disease. The odds are pretty good.
3. In my profession as an educational psychologist, I'm used to talking about statistics, using the language of probability and odds. Who sits where along the bell curve, who is in the top 10%, are we able to predict X% growth in reading proficiency, etc. Little did I know 2 1/2 years ago that my knowledge of statistics would become very personal.
4. Two and a half years ago, I was training for my 3rd Bolder Boulder. I was running 4 miles a day. I loved to hike with my husband and two daughters each weekend at NCAR or Chautauqua. The year before, we hiked the Great Wall of China! I had been a principal in DPS and was getting ready to launch my private practice. Everything was going great. I was your typical Colorado working mom living the Colorado dream.
5. Little strange symptoms were popping up, though. I unfortunately blamed my symptoms on the living Petri dishes I encountered on a daily basis, AKA Kindergarteners! And being a Type A personality, I kept going. Until one day, after 6 trips to the ER, I got

the diagnosis: Eosinophilic Granulomatosis with Polyangiitis, or Churg-Strauss Vasculitis, Stage 3. A true rare disease. The next thing I know, I'm on 120 mg of prednisone, Imuran, and receiving intravenous immunotherapy via a port in my chest. I'm in the hospital for scleritis where I've lost vision in my right eye. I've lost the hearing in my left ear. Later, I had reconstructive surgery on my esophagus caused by the rogue white blood cells attacking my GI system. I'm on heart medication for heart inflammation and I'm on anti-epileptic medication for brain lesions. And, most troubling for me, I now use a walker due to neuropathy. The disease is relentless and indiscriminate. Long gone now are my Bolder Boulder training days.

6. There is no cure for my disease. My life is now all about "controlling" the disease with medication and living as long as I can. Things will not get better. My daughters will never again have the active mom they once had. My medication keeps me alive, at a very high price – both literally and physically.

7. When I was first diagnosed, I had several questions I needed answered: What was the survival rate? How is this going to affect my life? And, how much was this going to cost me and my family? You see, with systemic diseases like mine, I have medication for each organ system. On top of these, I have the "Big Gun" immunotherapy drug and daily maintenance drugs. The tricky part of having a rare disease is that you have few options available when it comes to medication. In my case, there is now precisely 1 FDA approved drug for EGPA vasculitis. One. And it is not cheap. You don't have to be a whiz at the game of Monopoly to know that when you have a corner on the market, you can pretty much name your price.

8. Due to the severity of my disease, I'm currently on disability and receiving disability payments. The payments aren't much and it's

been a real hit to our family finances being on disability. We have to really watch how much we spend now, particularly when it comes to my healthcare. A couple of months ago, I went to pick up a prescription that normally costs me $20, except this time it was $40. Twice as much with no reasonable explanation and no warning. Now multiply this by 6 for each of my effected organ systems. For one organ system in particular, my Gastrointestinal system, I had to switch medications because the previous proton pump inhibitor was starting to effect my kidneys. When my GI doctor told me this, he gave me a ton of samples to get me started (That should have been a red flag!). It was May and I was only going to be on this drug for about 3 months since I was scheduled for GI surgery in July. When I went to fill my prescription, I was blown away. Doing a quick calculation in my head, 3 months on this drug would cost me roughly $1,600 out of pocket- money we didn't have leading up to an expensive surgery. So I had to make a choice: either pay this, go back on the previous PPI that was damaging my kidneys, or white-knuckle it for 3 months until my surgery. I took a gamble, white-knuckled it and risked further damage to my esophagus, making it hard for me to eat. No one should have to make that kind of choice.

9. But getting back to statistics and why they are now even more important in my life. As it stands right now and based on how active my disease has been, my care team has said I have a 50-50 chance of living 5 years. 5 years out is right around the time my daughters graduate from high school. I want nothing more than to see this happen. This is my plan. But a key factor in this plan involves me having consistent access to reasonably priced drugs, with no surprises. These are the drugs I need to keep me alive to come out on the winning side of those odds.