

Chair Hoffman, members of the committee, thank you for the opportunity to testify today. My name is Sarah Kasner. We are a family of six, including my husband Dan and 4 boys with initials A, B, C and D. AJ, Ben, Caleb and Duncan, who only responds to Dunky.

We have not one, but two boys that suffer from a rare, genetic, progressive and terminal disease called Duchenne Muscular Dystrophy. For those that are not familiar with Duchenne, it exists because kids lack an essential protein, called dystrophin that helps muscles get stronger. Every single movement that Caleb, 9, and Dunky, 7, make, makes them weaker as the muscle is replaced with fatty tissue. This eventually ends with the lungs and the heart. Life expectancy is generally late teens or early 20's, but far too often I read about kids that are much younger dying from Duchenne.

Our kids can not do what typical 7- and 9-year-olds do. They need help with simple, daily tasks, that most take for granted. Things such as brushing your teeth, putting your jacket on, toileting, getting out of bed, putting night splints on before bed, getting in the car, the list goes on and on. This disease also comes with social issues such as anxiety, autism, ADHD and depression. Additionally, this disease requires daily steroids which cause serious behavior issues and weight gain. And guess who helps them? We do, as their parents.

We help them because it means more time with them, and we do not know how much time on Earth we will get with them. So yes, it means I would rather help my kids with toileting than not, if it means I just get even one more minute with them.

We help them because we also are not guaranteed tomorrow. I am a carrier of Duchenne. Caleb was diagnosed nearly 5 years ago. When he was diagnosed, the Neurologist asked if he could see his brother. After directing him to the lobby, it took just a touch to his calf muscles and 5 seconds of watching him play for us to find out that this disease affected not only our then 4 year old, but also his little brother. As a carrier, I am now followed carefully by a Cardiologist as I am at heightened risk for fibrosis of the heart. As if it wasn't enough that my kids have this disease, it could mean that I also may not always be here to help them.

My husband stays at home to be the main care provider, and I work full-time in a demanding job, while of course also helping with the boys, but I'm exhausted, all the time. I wake up well before the sun to help one kid go potty, after taking turns to help kids with various requests during the night. We tag team to get the kids ready for school. Once we get them off, I quickly get ready for work, work all day and then try to manage my schedule so that I can help with them after school or bring them to their various therapies or doctor appointments. At night, we have a routine and it takes both of us and has to start nearly immediately after dinner. And then, I pull out the computer and work. I work until I'm too tired to work anymore and to make up for the time that I chose to spend with my kids.

What if it were different? What if this bill passes and I could dial back at my regular job so that I could provide personal assistance services to my children under CDCS? What if it meant that I could live a more desired lifestyle for my kids and for my family?

Currently there is a 40 hr. household cap for CDCS which means that no more than 40 hrs. can be paid to one or both parents regardless of the number of parents available to provide care or the number of children receiving services.

Lifting the 40 hr. household cap will make a difference because I have not just one, but two little boys with failing bodies that would have their mommy by their side day in and day out if they had their choice. I also have two kiddos that have very high needs that are unique to them.

Thank you for the opportunity to share our story and for the willingness to understand the positive impact this would have on families like mine.

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