Friday March 1, 2019

Good Evening Senator Osten, Representative Walker and members of the Appropriations Committee, my name is Sharon Barbieri and I live in Meriden and am a part of Our Families Can’t Wait.

I have a daughter who has neonatal Marfan Syndrome. She is two years old and thankfully she is home with us but requires around the clock care. She is trached, vent dependant (24-7) fed via feeding tube, unable to ambulate on her own. She cannot roll over, crawl, sit or stand without assistance from an adult and her equipment which was all denied by insurance so we had to get them on our own.

We are trying to get assistance from DDS and have had a very hard time. We have had Madison on the Katie Beckett Waiver since August of 2017, and as of last month, she still has 169 people ahead of her. We have been denied all other assistance as my husband is a paid Firefighter for the City of Meriden and "makes too much money" to qualify for other assistance. We are grateful for what coverage we do have but it only covers in-home nursing for 200 days a year and only 16 hours a day. With that being said, we will be running out of nursing hours at the beginning of April and will not restart until the Fiscal year begins July 1, 2019. Leaving myself to be her primary and only caregiver as my husband has to work two full-time jobs to support our family.

The Katie Beckett Waiver Program is a program that allows the State of Connecticut Department of Social Services to provide Medicaid services to individuals 21 years of age and younger who have a physical disability and may or may not have a co-occurring developmental disability, who would normally not qualify financially for Medicaid due to family income.

Our daughter Madison has been defying all odds and writing her own story. We are beyond grateful for the medical teams who have been able to help us thus far. She has gone from being in the 5th percentile in height and weight to the 95th percentile. With the help of Birth to Three program our daughter has been moving mountains. We are hoping that we can continue on this path, keeping her healthy and strong at home as she has been with your help of getting us more coverage. I am no longer able to transport her in a vehicle, on my own without a nurse or someone driving us to doctors’ appointments, as she needs to be monitored and suctioned multiple times. With this being said, if she were to become ill or even my son, I would have to call 911 and have them transported and that breaks my heart, instead of driving them myself with a nurse in the car. I have met so many families while we have been admitted to Connecticut Children's Hospital right down the street who have been in our position. Some who have finally made it to the top of the Katie Beckett Waiver List, and some who are still struggling to keep their children at home and out of the hospital and/or long-term facilities. Our children are our world and would
do anything for them. And with your help we can do just that. It is so much better having them home under the same roof with their families, versus being hospitalized or in a facility and be at a higher risk of becoming more fragile as they are more likely to get sick with the amount of germs they are exposed to.

I urge you to fully fund DDS services and to support HB 7092 to expand the Katie Beckett Waiver. We will do anything to help our little girl. This is her and her twin brother Jake. Thank you for listening to my testimony.