Good afternoon. My name is Santina Ragonese, and I am the mother of a medically complex child. His name is Gabriel. I am here today to testify in opposition to HB 7148, An Act Concerning The State Budget For The Biennium Ending June Thirtieth, 2021, And Making Appropriations Therefor. I oppose the budget because it cuts hospitals.

At nine weeks old, my son was diagnosed with Williams Syndrome. It’s a rare life-threatening genetic disorder that affects all areas of the body, primarily the heart, as well as intellectual and cognitive delays. At the time of his diagnosis, we were living in Florida. The doctors at the Children’s hospital where he was treated advised us to take him home or find another hospital, as his condition was beyond the scope of what they could do, and they gave him a year to live.

I was not giving up on my son and knew I needed to find someone who would help him. I am originally from Connecticut and after researching his condition, I knew the care here was better than what Gabriel would receive anywhere else. I moved back to Connecticut – to Old Saybrook – solely for the medical care, so he could go to Yale New Haven Children’s Hospital and have a chance.

When you have a child with so many specific medical needs, the care has to be 100% perfectly coordinated. My son has had more than 18 doctors at one time, including cardiologists, surgeons, anesthesiologists, endocrinologists, geneticists, and more. The entire team has to be in perfect unison. There can be no room for mistakes.

We spend a great deal of time at Yale New Haven Children’s Hospital and we will continue to do that for my son’s entire life. The feeling I get is that the doctors and staff are here because they genuinely are deeply committed to working with these children, and they sincerely care about them. It is imperative you have a team who has the both the competencies and the heart, and who connects with the families. This is what we have always received at Yale New Haven Children’s Hospital.

Today, Gabriel is 8 and he is doing beautifully and thriving, but it will be an ongoing journey. I attribute a great deal of that to the exceptional care and support his medical team has given us. My son recently had his eighth surgery in December. When you let go of your child and know his doctors and medical team are holding his life in their hands, you need to believe and feel they are the best of the best. I feel that with them. And it scares me knowing that these hospital budget cuts could jeopardize that care.
I’m here as a mother as well as an advocate for the care my son receives. We need Yale New Haven Children’s Hospital to remain strong, with excellent staff and with care that is highly coordinated, as Gabriel’s life literally depends on it.

So I ask you – for myself and for my son, and for all of the other families like ours – please do not support a budget that cuts hospitals.

Thank you for your consideration of our position.