

**Public Testimony for bill HB 6580**

**Testimony for Public Hearing**

**Public Health Committee**

**February 20, 2015**

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**Dear Representative Ritter and Senator Gerrantana**

**I am testifying in favor of House Bill 6580 The act to establish an advisory council for rare and genetic disorders. I am before this committee today on behalf of my son Michael because of his genetic disorder Short-chain acyl-CoA dehydrogenase (SCAD) deficiency is a condition that prevents the body from converting certain fats into energy, especially during periods without food (fasting).**

**I am forever grateful for the laws put in place for newborn screening for these disorders because they probably saved my sons life. This diagnosis has sent my family on a long journey over the past five years with many bumps and bruises that we would like to iron out for others and help prevent for ourselves with the creation of an advisory council.**

**My journey begins with the newborn screening, my son Michael turned out physically perfect at birth, and little did we have any idea that genetic screening was even completed at birth. After we took him home we got a somewhat harried call from a Nurse Practitioner of a Genetics office that we had to ensure that we fed Michael every three hours and that we needed to make an appointment to see the geneticist. My wife and I both having medical backgrounds continued to ask why, but wouldn't get a straight answer about what was wrong. It took until I told the Nurse Practitioner that I refused to set an appointment unless I spoke directly with the Geneticist as to exactly what was wrong.**

**This brings about issue # 1 that could be addressed by an advisory council- material on the newborn screening available in the hospital or a reference website with an explanation of the screened diseases. This would potentially assist new parents and not send them into a panic over their child's diagnosis.**

**The first decision I had to make for my son Michael- aside from his name was choosing an insurance policy. This was just prior to Obama care, the policy I chose was a high deductible plan, as at the time I believed that my son was healthy. This ended up costing me in the long run as it is practically a guarantee that at least once a year if not more he ends up in the hospital. If he can't eat he has to have an IV of dextrose until the time he is able to eat himself. I am constantly paying medical bills as hospital bills are outrageous, especially since he is only in for less than 24 hours.**

**This brings us to issue #2-possible changes in insurance coverage for rare disorders or people who are frequent flyers to the hospital system that an advisory council could address.**

**After meeting with the Geneticist and getting an understanding of Michael's diagnosis we were apprehensive scared but exited to have our son in this world. We were given instructions and a letter that specified treatment for our son to other Doctors incase of an emergency in which he could not eat. I though this was like the golden ticket for emergency rooms to ensure that he gets the treatment that he needs immediately. Little did we know how few emergency room doctors have limited training in rare genetic disorders and how life threatening the situation can become without immediate treatment. Our first experience was with Yale Children's hospital. This seemed to go well as our Geneticist was from Yale. We were admitted and an IV started reasonably quickly. He was in hospital for about 18 hours and the total charges were over \$ 8,500. Lucky for me I chose that high deductible plan. About the time I ended up paying off his first visit is when he went in for his second.**

**This brings about issue #3 that could be addressed by an advisory council. The ability to change ones insurance policy level within the same company once a person is added to a policy.**

**My wife and I decided to find an alternative Geneticist as we felt like our first was more interested in family history and their research than focusing on the needs of our son. This also meant changing hospitals as not to be under the care of Yale children's. We met up with the head of the Pediatric Unit at Bridgeport Hospital Dr. Beth Natt. She gave us assurances and made us feel comfortable that when Michael entered the hospital he would receive proper care. We figured if we preplan we would have a positive experience. While this was true of our**

**experience on the pediatric floor after our sons surgery, and the level of respect and caring by Dr. Natt's team on the pediatric floor. The same cannot be expressed for the emergency department. We had serious issues with the emergency room Doctor who was inept in understanding the crisis my son was in and placing his life at risk despite haven been given the instructions that we brought from the Geneticist. My wife had to begin to yell at the staff in order to get immediate treatment as my sons eyes began rolling up into his head from lack of treatment.**

**This brings issue #4 that could be addressed by advisory council, proper hospital training and treatment protocols to ensure expedient service when a person is in crisis and to ensure that parents are not marginalized or handled in the process.**

**My son has reached his 5<sup>th</sup> birthday and as I look towards the future I know that there will be many more issues we will have to contend with regards to his genetic disorder, especially within the school system and having teachers understand the cues to when Mikey is running low on energy. I am sure some of his disorder will be labeled as behavioral problems and we will have to educate people about our son. As he laughs and smiles, has a heart of gold and learns to manage his disorder himself I hope that good governance can make his path easier. Unfortunately he already understands that if he doesn't eat he has to go to the hospital and get needles.**

**Sincerely – Dominic M. Cotton MHA**