

Good afternoon Chair and committee members:

My name is Teresa Benson, I am from Polk County and I am here to testify and to ask for your support for HB 2390.

My granddaughter Megan was a beautiful, healthy, fun-loving little girl who was confident, smart and full of love. I will never forget how amazed I was by her bravery when my husband and I took her to the pumpkin patch in 2013 and they were offering helicopter rides. Megan wanted a ride in the helicopter. We called her parents to see if it was okay and then I explained to her that it was just a two-seater and that I couldn't come with her, it would just be her and the pilot. Only 8 years old she said, that's okay grandma I don't care and off she went without a care in the world to ride that helicopter.

Then 5 years ago everything changed. That brave little girl became a scared little girl who struggled with every aspect of life. She had terrible separation anxiety and couldn't be away from her mom. There were no more trips to the pumpkin patch or other fun places, it was too stressful. Even going to church was a struggle for her. Crowds were unbearable, the noise was unbearable, even certain patterns triggered strong reactions. This strong-willed, confident little girl could no longer make any decisions. You couldn't even ask her a simple question about what she wanted to eat because she could not answer you and if she did answer you, she was afraid. Afraid it was the wrong answer even though there was no right or wrong answer. She suffered from tics and would often repeat words that made no sense and had nothing to do with what was going on or the conversation at the time.

One of the hardest things for me was that she could no longer say "I love you". She was always such a loving child and would hug me and say, "I love you grandma" and if grandpa wasn't there, she would always tell me to tell him she loved him too. It would be years before I would here those sweet words come out of her mouth again. Even today it brings tears to my eyes to think about it.

Then Megan was diagnosed with PANS. Now we know what's wrong with her we can get help and she can get better. But instead we found out that treatment was very expensive, and the insurance didn't cover any of it, they didn't even recognize it as a real disease. Her parents didn't have the money for her treatment and neither did we. This caused a great deal of stress and anxiety on top of everything else, but in the end, we were blessed by people who loved Megan and had the money to help. Donations came from in from people at church and a GoFund me account and she was one of the fortunate ones who received the treatment she needed which included two IVIG transfusions.

Today Megan is 16 years old, she is thriving again because she was able to receive the treatment she needed. Other children with this disease are not so lucky, they need treatment, but they don't have the money to pay for it, so they and their families continue to suffer needlessly. I beg you, please support HB 2390 and help these kids get the help they need to get well.