

Chairman Scott Lipps, speaker Robert Cupps, and the entire Health Committee,  
Thank you for your time today and having us here in support of House Bill 488 which is to cover insurance for PANDAS Disorder.

My name is Anne Golden and my daughter has PANDAS.

After a long journey, confusion, and multiple misdiagnosis, my daughter Ella was diagnosed with PANDAS disorder in January 2019 as a 13 year old 8th grader, a traumatizing day that changed the direction of our lives forever.

Prior to her illness, Ella was a typical teenager, exceptional student, four sport athlete, had a core group of great friends, and was always on the go ready for anything with a smile on her face and energy that seemed to last for days! She dreamed of exceeding district basketball records like her older brother, and was on pace to do just that!

Then, in September 2018, Ella had strep throat. Not long after, she quickly started to change. She developed extreme anxiety to the point she was unable to participate in her classes. She couldn't get up in the morning or get out of bed. Sometimes I'd have to take her to school late, only to have the school call me to come get her because she would cry relentlessly due to the anxiety that PANDAS causes. She lost her ability to solve math problems, her ability to focus became nonexistent. It didn't stop there. Her symptoms started to spiral out of control. She developed severe OCD, food restriction, tics, insomnia, depression, & rages. She sadly lost her will to live.

One night Ella told us she didn't want to live anymore. We were heartbroken. We took the advice of others and decided to admit her to a children's psychiatric hospital. She spent 5 days there. Sadly, this was not the answer for her treatment. It was just another expense for us with no answers as to what's causing all this in Ella.

On January 13, 2019 Ella had a terrifying seizure episode with tics. She was unresponsive. Her eyes, hands & feet were moving a mile a minute uncontrollably. After talking to an old friend, who's daughter has PANDAS, she suggested that we see their specialist.

On January 24, 2019 Ella saw a specialist who diagnosed her with PANDAS DISORDER. We were relieved to get a diagnosis, but terrified at the same time. He immediately prescribed antibiotics, prescription medications, & countless supplements.

Unfortunately, Ella didn't respond to the medicine like we had hoped. Her specialist changed medicines several times over 6 months. Within those 6 months, Ella became severely agoraphobic. (Which is fear of leaving the house). Her anxiety became so debilitating she's scared to leave & still is to this day. She won't see her family or her friends at all! She would confine herself to her room only. She had severe depression, physical tics, verbal tics, insomnia, intrusive thoughts, nightmares, OCD, & rages. Her memory is fuzzy & she also suffers from both visual & auditory hallucinations.

We saw her specialist in June 2019 where he told us nothing is working & Ella needs IVIG. They submitted her case to our insurance, but we were sadly denied treatment. It was devastating. We couldn't afford IVIG & were at a loss. My close friend talked us into setting up a Go Fund Me

for Ella. My son, Ella's older brother, designed Pandas T-shirts to sell to raise money for his sister's treatment. Two of her friends even sold their hogs at the county fair to raise money for her! Our community raised over \$50,000 to help cover the cost of treatment. Can you imagine the widespread support of our community to be able to raise that amount of money? We were so overwhelmed, yet disappointed. Disappointed in the fact that if her disorder had another name, another diagnosis code, it would have been covered by insurance & our friends and family wouldn't have to dig deep into their pockets and bank accounts. But they did it for her, and I will be forever grateful.

Ella had her 1st IVIG treatment in August 2019.

It was a fight to get her there. She was TERRIFIED to leave the house. She had panic attack after panic attack after panic attack in the days leading up to IVIG. Her specialist had to prescribe a sedative for her to take the day of. Thankfully, we got there.

You see, kids with Pandas live in this body and have a mind that works against them. Ella's brain is on fire. It misfires & sends signals telling her lies. She constantly has to fight her thoughts along with all her symptoms she fights on a daily basis. She's dying to be normal... To be herself again.

What I can't express to you enough is that Ella was a typical teenager, a four sport athlete with an amazing core group of friends, up at the crack of dawn, doing her hair and ready for ANYTHING! She was happy, energetic and always always always on the go doing or going somewhere with her family or her friends. PANDAS STOLE MY CHILD.

She's a child who I don't recognize. A child that doesn't want to shower or leave the house or see anyone. A child that doesn't want to live. A child that deserves more.

With IVIG, we have seen improvements. She had her 2nd IVIG in March of 2020. She started an Instagram account to support other kids with PANDAS and is an inspiration to so many. She started believing in herself again. After 2 years of the inability to take classes at school, she is taking 4 classes. She has less hallucinations, is less agitated, and is out of her room more with us as a family in the house. But her fight is not FAR from over. She still suffers from countless debilitating symptoms. She needs more consistent IVIG therapy. We need YOUR SUPPORT and we need it now!

This can happen to anyone's child. I ask you to PLEASE pass House Bill 488 and help heal my child, along with so many other children going through this debilitating disorder. It is Hell for the child & their families.

I'm now able to take any questions you may have. Thank you for your time.