

Mackenzey Infanti
1315 Commerce Street
Wellsville, OH 43968

May 14, 2022

Dear Chairman Lipps, Vice Chairman Holmes, Ranking Member Liston and Representatives of the Health Committee.

My name is Mackenzey Infanti, I am a soon-to-be sophomore at West Liberty University, and I have PANDAS. When I was a little girl, before the age of 10, I was quite happy, healthy, fiercely independent and very confident, many describe me as “cocky confident”. I was a straight A student and leader in my class and excelled in math and science. I developed strep many times as a child and recovered normally. That all changed abruptly in the spring of 2012, after a strep infection. Let me remind you that I was 10 years old. I am now 20. I started having anxiety at school, nightmares, separation anxiety, and increased sensitivity to sounds and smells. I suffered from brain fog, some days not able to even add $4 + 4$ and eventually I was no longer able to attend school. . But this was just the beginning of a living nightmare. In the fall, my pediatrician sent me to a psychologist. Weekly exposure therapy appointments turn into months, still with no answers. This turns into 22 months of hell, not only for myself, but for my family. Three therapists, and leaving my pediatrician later, we finally found a doctor who diagnosed me with PANDAS.

Having PANDAS makes your brain feel like a computer. Your mind is filled with hundreds of frustrating tabs that you would use on a computer, but you can't click them away. Imagine that. We are children, not office workers. I live with anxiety, depression, OCD, PTSD, sensory processing disorder, and ADHD affecting my life every day. We have one childhood, and mine has been ripped away from me overnight. I am running a marathon with no finish line. Those with this illness do not know what their future will look like with their health.

After weeks of phone calls because of first denial and creating an appeal, I finally got my first IVIg in August 2020, 6 years after my diagnosis. That shows how long this disease takes over. So many emotions, fear, hope, pain raced through my mind. I was blessed that I got it. After treatment, I often cried tears of joy to my mother. All those tabs were gone, I felt free! I always tell her, “I wish we did it sooner,” because I did not know that it was going to have such a positive impact on my life. I know there are still many kids who aren't so lucky. I do not see how someone can see an innocent child and say no to saving their life. Today I am speaking for those kids who cannot share their voice because they are afraid of their own life.

3 IVIg's later and I have just completed my first year of college. Without those treatments I would not be able to stand in front of you today. I worry about my future. I worry that I will get denied another IVIg again. One treatment is equal to the tuition of one year in college. While I could be using that money for my education, I fear that I may not be able to graduate without it. With this law, my own and other kids' futures can be a whole lot brighter. I have been sick longer in my life than I have been healthy, but I will never lose this fight. Thank you for your time and consideration.

Sincerely,

A handwritten signature in black ink, appearing to read "Mackenzey Infanti". The script is cursive and somewhat stylized, with the first name being more prominent.

Mackenzey Infanti