Hi. My name is Clara and I am 11 years old. I live in Lisbon, Ohio. Thank you to Speaker Cupp for having me here today. Thank you to the Ohio Health Committee and to Chairman Lipps for having me here today.

This is so important to me… Because I have PANDAS.

When I was 7, I was a normal girl. I loved zebra print, dancing, watching netflix, writing, spending time with my friends, and art. I had good grades and I liked going to school. I was the class clown and had a lot of friends.

I went to school one Friday morning in the first grade and I felt great. That night I suddenly had jerky body tics while watching a movie. I could not control my body. If I tried to stop the movements, then the tics would get worse. It was a feeling in my body that I just had to get out. I thought this was normal.

My mom took me to many doctors. Nothing that they did helped my tics. The medicine that the doctors gave me made me sleep all day. My tics got worse. I would slap myself hard during a tic and leave bruises and marks on my legs. I would slam my head against the car window because of a tic and then have a bump on my head. I had a hard time sleeping because the tics would wake me up.

At school, my friends stared at me. They made fun of me. They asked me "why do you do that, Clara? Are you stupid or something?" My close friends even stopped being my friends. I remember I sat alone at lunch one time because no one would sit with me.

There were times I could not write and I accidentally threw my pencil across the room because of tics. I began to have ankle and joint pain because of the repetitive tics. I had to stand all day in class so that I was able to get the tics out of my body. My classmates told me that I was weird and they mocked me.

I had terrible OCD that made me hate the number 9. If I had to write, read or hear the number 9, my tics would be worse than usual. Math class created anxiety for me.

I stopped being my normal self. I was sad and tired all of the time.

The OCD also made me hate to wear certain clothes that did not feel right on me. If I wore the clothes that my brain didn't like, then I would have more tics that were loud and forceful. One time I threw a tantrum because I wanted to wear my socks inside out and my mom did not understand why and she made me change them. We were late for school that day.

Months later, my mom found a doctor who told me that I had PANDAS. He gave me a different medicine called an antibiotic. It helped me a lot. The antibiotic made me feel like my normal self again.

My friends treated me better. I could do my homework easily. I was back to wearing all types of clothing. I was happy. I thought that PANDAS and tics were behind me.

But after a few months I had a PANDAS flare and the tics came back. The tics were worse. I did not want to go to school. I had to have extra help in school with Math. I missed a lot of school. The school nurse would call my mom to pick me up because I was too tired from having tics all day or the tics made my body hurt too much.

I began to not like myself but I did not know why. My brain told me that I was not good enough. My mom and family told me all the time how amazing and beautiful that I am. But that did not matter. The PANDAS told my brain that I hate my life. The PANDAS told my brain that I do not want to live anymore. The PANDAS told me that I am stupid and ugly. If I tried to tell the PANDAS and my brain that they are wrong, then my tics would increase to a horrible level. My brain and PANDAS told me to kill myself. I told my mom that I didn’t want to live. I told my mom that I didn't care if I died… at age 7.
Because of this, my doctor ordered IVIG. At first, I was scared to have IVIG. But after the IVIG I felt better than ever. My tics were gone. I was happy. I was my funny self again. Everything was normal. My brain was happy.

Since then I have had some flares. But, my doctor always helps me with my medicine and IVIG.  The medicine and IVIG always help me to feel better and be myself.

My mom is a nurse and she had to argue with our insurance to pay for my IVIG.  This makes me sad. All insurance should pay for IVIG and PANDAS medicine.

PANDAS and PANS are similar to other illnesses such as heart attacks, cancer, the Flu, or even Coronavirus. If insurance can cover treatments for these illnesses, then why wouldn't they cover treatments for PANDAS and PANS? Do they want us to feel bad?  Do they want us to do bad in school?  Do they want us to try and hurt ourselves or even worse, commit suicide? Do they think that we are not worth it?

It is hard for me to speak to you about such embarrassing things that have happened to me because of PANDAS. But I am here telling my story because I do not want one more child to suffer or go through what I have.

There are some kids who are worse off than me with PANDAS in Ohio because they can not get IVIG. They deserve to have IVIG or any treatment it is that they need.

This is your chance to help. I am asking you to please approve house bill 488 so that children with PANDAS and

PANS all over Ohio have the support that they need. Please say yes so that no one else has to suffer.

Thank you for listening to me. I will now answer any questions that you have.