

Thank you for taking the time to hear our testimony today. My name is Shannon Wright. My husband is Mike Wright. We have been married for 21 years. We have three children Alyson and Ashleigh who are twins and seniors in high school. Our youngest, Matthew, is a sophomore in high school. I am a social worker and my husband is a law enforcement officer. Through our professions, we have seen and experienced many situations which may be upsetting to many. Even as seasoned professionals in our fields, nothing could have prepared us for what happened in our own family. While writing this testimony, I have struggled with reading through it without breaking into tears. It surprised me at first. This happened nine years ago. I think it speaks to the level of trauma we experienced during that year, revisiting it brings it back. Please excuse any emotion as I attempt to tell Alyson's and our story.

Alyson was in many ways a very typical little girl who loved art and had spent the summer writing and illustrating a book of fairy-tale type stories. She was friendly and enjoyed playing in the neighborhood with friends. Then everything seemed to change.

On Sept. 13, 2011, I knew without a doubt that something was terribly wrong with my daughter. That night my little girl was completely overwhelmed with fear. She vacillated between being in the fetal position in the corner of the couch, screaming and sobbing uncontrollably, running through the house checking locks and seeing if everyone in the family was safe. She was convinced someone was scratching on the garage door and trying to get into the house. She told me that someone was listening to us through the phone. It went on for hours. I was unable to comfort her, and all I could do was hug and rock her as she begged me to make the unseen terrors stop. The sudden change in my normally sweet-natured 9-year-old daughter came on with such intensity and ferociousness, I felt as though the wind had been knocked out of me. Alyson was not the same after that night and it would take months to get her back.

In the school setting and at home, Alyson became increasingly unresponsive much of the time. She lost her ability to maintain her concentration and complete her assignments. She could not remember basic information like her birthday. She began crying and hiding under desks. She would pace back and forth, making continual, random and strange comments. She had sudden mood changes becoming violent and a flight risk.

For a two-month period she was homebound and unable to leave the house. She was unable to fall asleep. It was not unusual for her to be awake and agitated until 3 or 4 in the morning. She would beg me to kill her. She wanted me to drain all the blood from her body. When she went back to school she would punch and bite the staff and was constantly being restrained or secluded. During a particularly low time, I had fallen asleep on the couch out of pure exhaustion while she paced back and forth from the kitchen to the living room, stopping to hop between the couches and muttering to herself or saying "Yeah, sweetie" over and over. I woke up suddenly to find her gone. I searched the house and ran outside barefooted in the cold to see if I could find her. When I didn't immediately find her, I got into my car and drove around the neighborhood. After a frantic search, I found her in the back of a patrol car rocking and talking to herself, unable to tell the officer the names of her parents or where she lived. After that event,

we started setting the house alarm at all times. Not to keep intruders out, but to alert us when she left the house.

My husband and I were unable to explain what had happened to her. After her sudden onset on September 13, 2011, I had immediately called and made an appointment with the pediatrician. He was sympathetic, but instead of running any tests or investigating further, we were referred to the psychiatry department at our local mental health clinic. I knew in my gut this was not the answer, but followed the doctor's suggestions like good parents do. My fears were that something catastrophic medically had happened to my daughter. I wondered if it was a cancerous brain tumor or a stroke. The only experience that I can compare it to is when I was caring for my grandmother who had Alzimers. She looked the same, but everything was different. It was a similar experience with Alyson.

It took far too long to get the intake appointment at the mental health clinic and after advocating with another social worker who had the exact same degrees as myself that we did not need to begin with therapy and instead needed an emergency appointment with a doctor, they finally agreed. The psychiatrist was kind and patient. He made room in his schedule to see her weekly and sometimes twice a week. We tried many psychotropic medications without the healing results we were looking for. He ordered blood tests and an MRI. He referred us to a neurologist who ordered more blood tests and an EEG. It only fueled further frustration when her results came back as maddeningly normal. I needed answers, but instead there was nothing. As an LMSW with 18 years experience working with children in residential treatment facilities, mental health clinics and schools, I had never seen anything like this. Instead of working with clients, my family was the client. It was an eye-opening and humbling experience.

The search for answers became all-consuming for me. When I wasn't providing care for Alyson, I was searching the internet for any possible answers. I was grief-stricken, filled with fear and losing hope. I frequently cried during doctor visits while describing her current symptoms. I endured multiple and lengthy meetings at Alyson's school, trying to develop a plan that would work for her. I felt myself becoming immobilized and not knowing where to turn. Coping with the changes in Alyson created an unprecedented strain on our entire family. We were all sleep deprived and increasingly more anxious ourselves, waiting for the next onslaught of uncontrollable behaviors. My husband worked nights as a law enforcement officer and probably had the least amount of sleep as he was provided care for Alyson during the day while I was at work. He was so worn down and became ill with pneumonia. Alyson's twin sister, Ashleigh, developed mono and was home from school for a month recovering. Matthew started having nightmares and teachers complained that he was becoming more withdrawn at school. Our families' physical and emotional health was starting to break down under all the stress. Ashleigh and Matthew started to refer to events in our lives as being before or after Alyson "lost her mind". At one point my 7-year-old son solemnly stated to me, "If Alyson doesn't get better, she is going to have to live with you forever." He was merely putting the fears in my head into words. The future seemed very bleak for my daughter.

Every night I would search the internet, entering in my daughter's symptoms, looking for any answers. During a February psychiatry appointment, the doctor had mentioned that her symptoms had an OCD type presentation. That night I googled "sudden onset OCD". It was the magic word combination. PANDAS popped up on my screen. As I read the description, I literally stood up and yelled "This is it!" I called my step-father who is a physician and asked him to send me any research articles regarding PANDAS. Armed with a new direction, I began reading articles from those medical journals and bringing copies of the articles to my appointment for Alyson. Interestingly, at the same point when I was becoming aware of PANDAS, Alyson's child Psychiatrist was also considering it as a possible explanation for Alyson's sudden change. Ultimately, the doctor's encouragement and further research led me to a parent resource website and a pediatrician in Chicago who began diagnosing patients with PANDAS/PANS and treating it with antibiotics, steroids and intravenous immunoglobulin (IVIG). After reading Alyson's information, Dr. Miroslav Kovacevic was the first doctor who said to me, "I know what she has and I can help her." He was also the first doctor to accurately describe the life that we had been living since Alyson's onset with uncanny accuracy. He described the shock, the grief, the search for answers by visiting with multiple doctors before finding him (he was our 5th doctor! Not including the two that I am related to), the suspicions others in the community seemed to have on us and even the late night internet searches. He told me I should be very thankful for the internet because if this had happened 10 years prior we would not have found each other. He encouraged us to find support among other PANDAS/PANS parents as what we have been living through had been very traumatic.

It was a game-changing decision and the answer to hours of prayer to contact Dr. Kovacevic and pursue IVIG for Alyson. Dr. Kovacevic explained that Alyson had a type of autoimmune issue in which strep or other kinds of infectious agents can trigger her antibodies, which mistakenly start attacking her brain. The IVIG would flood her body with healthy antibodies and with time this would allow Alyson's brain to heal. We were cautioned that the change would not happen immediately and the success or failure of the treatment would be determined at the three months post IVIG. We paid the cost for the IVIG upfront which was over \$10,000 at the time. Charging it on a credit card. Dr. Kovacevic followed her for the next year. We provided him with email updates. He prescribed her ongoing antibiotic, but told us that we would need to find our own local providers to take over after one year.

No other treatment attempts brought the healing that IVIG did for Alyson. She slowly came back to us. Dr. Kovacevic said that healing would come with two steps forward and one step back. He would consider it a success if she came back to us with a 90% reduction of symptoms. He said she would likely have 10% of the symptoms that she would continue to struggle with. This was also proven to be true. Alyson healed over the summer. She went from people suggesting she be hospitalized long term or placed in an alternative day program like Project PLUS in Topeka, to being enrolled in the general education classroom in her home school with support. We did find a somewhat local team including Dr. Kobashi to provide follow up appointments and support. Alyson had another big regression in middle school, but Dr. Kobashi immediately prescribed another IVIG. This time we were able to have the procedure done in Kansas and even at home through an infusion company. We also had much more community

support. The second infusion cost \$12,100. When our friends, church members and family heard she needed another infusion, checks started coming in the mail. When I stopped to count them, it was exactly \$12,100. Absolutely miraculous. It is the way it should have been at the beginning, treatment quickly delivered in Kansas.

Alyson is now a senior in high school. She is taking a freshman comp class for credit at Washburn University. She will graduate with a 3.3 grade point average. She has an iep, but utilizes very little support at this point. She has transitioned well to change demanded by COVID and online classes. She has been holding down a part time job at a local thrift store working 15 hours a week. She plans to attend Washburn University next year and major in Nursing. None of this would have been possible without treatment.

Thank you again for listening to our story.