

Thank you for the opportunity to testify in front of the House Insurance and Pensions Committee today. My name is Shannon Wright. I am a Masters level social worker licensed in the State of Kansas. I have been practicing social work for the last 28 years primarily with children and families. I am also a mother of a recovered PANS patient. Her sudden onset was at age 9 and was completely debilitating. She is now 18 years old. I credit her recovery to our ability to access IVIG as part of her treatment. She is graduating from high school this year being a model student, working part time and planning on attending college and pursuing a degree in the medical field.

This illness is not only devastating for children, but it also affects the family, school systems and the community. Caring for someone with PANS/PANDAS comes with unique challenges and is often scary and unpredictable. This can result in high caregiver burden and stressing the school systems who have difficulty with coping with sudden changes and extreme behaviors. The pilot program proposed will allow children and families to access medical treatments which would appropriately address the underlying causes of the behaviors the children are experiencing.

I think there are several factors to consider as we move forward: 1) Offering the coverage to a broad enough population in order to “catch” enough cases to give the State of Kansas enough data in order to complete a cost benefit analysis. Different groups who could be considered are state workers, school district employees or those employed at Kansas Universities and medical centers. 2) Making sure of the children identified to take part in the pilot truly are children with PANS/PANDAS. It may be considered who is making the diagnosis such as an immunologist, rheumatologist, neurologist or other PANS/PANDAS knowledgeable provider and 3) specifically naming the treatments that will be covered when treating PANS/PANDAS. Antibiotics, steroids, ibuprofen and a variety of psychiatric medications are already generally covered by insurance. IVIG is the most expensive (and in our experience the treatment that made the most impact) is routinely denied by insurance.

Thank you again for your interest, time and consideration of our bill.