STATE OF KANSAS HOUSE OF REPRESENTATIVES

STATE CAPITOL TOPEKA, KANSAS 66612 (785) 296-8621 john.eplee@house.ks.gov



163 DEER RUN ATCHISON, KANSAS 66002

JOHN R. EPLEE, MD

Testimony House Insurance & Pensions

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Thank you, Chairman Johnson, Vice Chair Croft, Ranking Minority Neighbor and members of the House Insurance and Pensions Committee for the opportunity to address you today on this important topic of insurance coverage for diagnoses of PANS (Pediatric Acute Neuropsychiatric Syndrome)/ PANDAS (same disorder but associated with streptoecocal infections).

These diagnoses were not known or certainly not understood even 15 years ago in medicine. But around 2010 we started seeing a recognition of these disorders in the medical literature and these diagnoses continue through today. We understand much more about these diagnoses than ever before and the wide array of treatments – some of which are quite expensive as you will soon hear.

My policy involvement began 3 years ago when I was afforded an opportunity to understand how catastrophic these diagnoses are to patients and their families. I further readily understood the wide array of treatment options available and how expensive some of them are – in particular IgG – costing anywhere from \$3,000 to \$5,000 per infusion. The treatment results were nothing short of a miracle.

So, make no mistake about it, PANS / PANDAS is real and definitive treatment is expensive. And so, this bill originated in the House Health & Human Services but after last year's hearing and interim study has been referred to your committee for review and consideration for placement in the SHEP or other appropriate defined population to evaluate cost impact going forward on all insurance plans in Kansas.

