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On Behalf Of:
Committee: Senate Committee On Health Care
Measure: SB628

My 8-year old daughter has suffered from PANDAS since before she turned 1. Our early concerns were either down-played or dismissed by our healthcare providers, and I was the recipient of many parenting-book suggestions. By the time she was 4 or 5, our providers could no longer deny that something was seriously wrong with my daughter. Her violent rages were occurring daily, and our other children were not safe around her. I spent many an evening locked in my room, my arms securely wrapped around my daughter as she flailed and wept and promised to slit my throat later than night while I slept. When I voiced my suspicion that her 'behaviors' were in fact symptoms of a neuro-psychiatric disease called PANDAS, my provider was quick to cast doubt on whether or not PANDAS was even real. He thought it was time to be referred to a psychologist instead, but most mental-health clinics refused to see our daughter - she was too young and her 'behaviors' were too severe. Others had waiting lists so long that they were no longer adding names. At age 6, we saw a psychiatrist, who recommended anti-psychotic drugs for our daughter. We were happy to have a treatment recommendation, but drugging a 6-year-old with anti-psychotics did not sit well with me. Instead, we decided to pay out-of-pocket to see a PANDAS specialist in Illinois. He confirmed that we were dealing with PANDAS, and he could provide treatment. But he warned us that many insurance companies would not pay for the treatment our daughter needed, and indeed our request for coverage was denied. Could we fly to Illinois and receive treatment at his facility, he asked. When we learned what the treatment would cost, and that we might need multiple rounds, we quickly realized no, WE COULD NOT AFFORD TO TREAT OUR DAUGHTER. Luckily for us, NWPPN took up our cause. With support from our employer, Nike, we were able to convince our self-insured medical plan to change their policy and include coverage of IVIg in their plan. But by that time, our daughter's treatment had been delayed for another year. She finally has received IVIg, and after just 3 rounds, done in our home, our daughter is now in remission. She laughs and sings and is thriving in the first sport she's ever participated in - wrestling. But our family has a long way to go to fully heal. I don't know how long it will take for our younger daughter, now 6, to feel safe in her own home. My husband says serving in Iraq was a cake walk compared to parenting a child with PANDAS. I hope, in the future, diagnosing and treating PANDAS will take a matter of weeks, and not the 7 years it took us. Please save other families from the horrific experience our family endured by passing SB 628.