

## HB 447, Health Insurance - Pediatric Autoimmune Neuropsychiatric Disorders - Coverage

Dear Representative Carr,

To reverse my 3 children's PANDAS symptoms, we have spent nearly \$100,000. Most of that was spent in the first 2 years to "get my children back." Below, I have outlined where exactly \$50,000 went. The rest of the money was mostly from taking time off work, paying nanny's when they were too sick to go to school for months and supplements to bring their bodies back to healthy baselines.

For my son, whom was the first and sickest, he required IVIG. For him, IVIG was a silver bullet after a year long battle. Since my other children were caught earlier and we knew what we were dealing with, only long strong courses of antibiotics (clindamycin) along with supplements were all that was needed. But, we are still fighting to keep them healthy.

This bill is extremely important since it not only helps families afford to get their ill children back, it helps explain to doctors that this is real and the children CAN be cured. MOST mental illnesses are caused from INFECTIONS. Infections can be cured. Lets work together to help these children and adults and prevent or cure mental illness that are caused from infections. My children will never get back the 5 years they lost of their childhood - which is most of their childhood, but they can go on to being healthy, happy adults. Other children will not be as lucky as mine were, unless you help them now.

Our out of pocket expenses paid for children due to PANDAS:

~\$50,000=

- Doctor visits (since the ones that treat or understand PANDAS do not take insurance) >\$7,000
- Antibiotics and other medicines co-pays >\$3,000
- Pro-biotics to give 3 hours after each antibiotic to reverse C-diff and keep from getting c-diff >\$1,000
- IVIG treatment (1 time for 1 kid) \$10,000
- Co-pays for tonsil & adenoid surgeries (for 2 kids) \$1,000
- Lab tests: blood, urine, fecal & hair >\$25,000
- Hospital emergency room co-pay (when my son was bruising and no longer could walk) \$50
- IQ air hospital grade air purifier plus replacement filters \$1,600

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The endless vitamins, tumeric (anti-inflammatory), purified water that they now need (since both immuno-compromised and because the public water was testing high in aluminum), GMO-free, dairy-free diet, months off of work I had to take, extra cost to hire a nanny to watch him when he was too sick to go to school for many months so I could work.

~Priceless=

These costs do not account for the ruined Disney vacations, my children still not being well enough to attend summer camps, not being able to walk or run long distances still, still not being

well enough to play on sports teams with friends since joints are in constant pain, not being able to participate in PE due to joint pain.

For the parents: mental & physical exhaustion and complete overwhelmed for many years. Taking extremely sick children doctor to doctor for any help, but instead being blamed for their issues, told this is fake or told "this is just the new normal for them" and sent out the door. Depression and feeling like a failure since your children are too sick to be children. Many PANDAS parents end up divorced.

Thank you for your consideration on this extremely important bill, which is SO much more than insurance coverage. It is a REAL start to addressing one of the causes of the real and serious mental health issues of today.

Sincerely,  
Autumn Metzger  
2/5/2020