

Attention Representatives,

On behalf of all families that have experienced the HELL of PANDAS/PANS, without adequate medical care and often ZERO care or concern shown to our kids... THANK YOU for caring and for fighting to have ALL kids receive the help they need!! This new legislature will ensure that these hurting children can find health and healing and be kids, again ..vs slapping on needless lifelong and wrong labels and pushing a lifetime of unnecessary psych meds... Drugs that often say on the label NOT to administer to kids.

Our personal HELL happened almost 15 years ago in 2007 when our now 20 year old son had just started Kindergarten. It was like someone had taken our sweet and compassionate son and replaced him with someone that looked like Mason but was a child consumed with doom and being tortured mentally and acting out behaviorally. This change happened overnight. He was repeatedly asking if he had done wrong things that he hadn't. He was having choreiform movements that involved uncontrollable shoulder shrugs and eye blinking tics. He was having auditory and visual hallucinations... screaming about the bugs crawling on him and yelling at the people on the TV to stop staring at him. He said his brain was telling him to do different things that he knew was wrong but he was afraid he might do anyways. His handwriting and cognitive skills declined. He was not listening to simple instructions and could not stay focused. His facial expressions became either blank like he was looking straight through us or he looked like he was being tortured mentally. His pupils were huge. He had to urinate frequently and said it felt like it wasn't all getting out. So he'd go again, and again, and again. Every few minutes, at times He developed severe OCD within a week ...having horrific thoughts and a fear of everything bad happening. One of the OCD thoughts that was most disturbing to him was his brain kept telling him that he didn't love me anymore. He repeatedly asked why his brain was telling him that and as a compulsion would say sorry or i love you sometimes up to 20 times a minute...to undo the bad thoughts that were torturing him. Usually the words "I love you" from your child melt a mommy's heart. Suddenly, those words were breaking my heart because they were evidence of the horror that was happening in Mason's mind. One night before bedtime ... which had become an impossible time of the day for a kid that used to crash and fall asleep within minutes...Mason said..." Why would God let this happen to me. If I were God I'd never let this happen to a little boy!" Gutwrenching. I tried to come up with encouraging words but I, too, had been wondering the same thing and was begging God to bring my son back. Then the next morning Mason matter of factly says... "I think I know why God is letting this happen to me. Maybe some day I'll be able to help other little kids this is happening to." FIVE years old...and Mason was teaching me something... There is Purpose in the pain. Lots of tears shed that day and the days to come. AND Mason was right. God has enabled us to help many people figure out the mystery of what is happening to their child, ironically ..even his best friend a few years later!

But it has been a hard road for us and thousands of others. And the medical community should be doing THEIR job and helping kids! PANDAS/PANS is a horrendous condition that wreaks havoc on kids and families. And the thing that makes it even more sinister is that in some states insurance companies do not HAVE to cover it .. which means doctors can keep their head in the sand and refuse to keep up with the research over the last two decades and pretend this

atrocities doesn't exist ... all to protect their income flow. Deplorable... And very opposite of that Hippocratic Oath they took when becoming a doctor... and disgusting that they are ok with participating in a scheme that ultimately prolongs the unnecessary suffering of children and families!

When we first started seeing the changes in Mason, we were terrified that he might have a brain tumor or some sort of brain damage. As I desperately tried to explain what was happening to the pediatrician, I remember saying the words.. it's like he is possessed ...and begging the doctor to help us. The doctor, who had helped our family through lots up to that point, with all four of our kids, was oddly dismissive . He said that it sounded like typical kindergarten behavior and maybe was due to us adopting a sibling 6 months prior!? I told him I had been the KG "room mom" in all of my kid's classes and have taught preschool and NOTHING was typical about what was happening. And that the adoption remark was ridiculous. At the next appointment I was excited because I had found an article from the [worrywisekids.org](http://worrywisekids.org) site on PANDAS and bad thought OCD and had burst into tears when reading it because it described what was happening EXACTLY. I had hope...because it had a name and an easy cure... Antibiotics and possibly ERP therapy. Again the doctor was dismissive and condescending...even chuckling at me and making fun of my Google search. I was heartbroken and infuriated. Google searches aren't just meme producing... they reveal many facts and medical journal articles, and i am a college graduate who can also read and understand medical journal articles.

We were referred to a child psychologist. I tried, again, to explore the idea of PANDAS. The practitioner, in her 60s, said she had never heard of that, there was no way it was that and proceeded to throw out all of the possibilities she was trying to choose from and noted that he probably had multiple diagnoses. The things she suspected were... schizophrenia, bipolar, autism, ADHD, OCD, ODD, tourettes, anxiety disorder, depression and others. And started discussing major psych meds. Again, he was only 5!...and previously, typically developing. And this happened out of the blue. My momma gut said there is NO possible way that Mason all of a sudden had every imaginable mental health disorder known to mankind. My social work degree brain knows that it is VERY rare for a child to be diagnosed with schizophrenia. We walked out that door and never looked back. I pray often for those kiddos that don't have momma's that follow their gut feeling and subsequently, the kiddos that suffer needlessly for years taking psych meds that make things even worse. A disgrace that this is happening in our country!! I called the practitioner/ author of that article i had found and she spoke to me for over an hour. Her words at the end bring tears every time i think about them..."you will get your little boy back!" I clung to that promise over the coming months and praise GOD we eventually did get Mason back! But it wasn't due to the care and expertise of the medical community. It was due to me not trusting them and their condescending indifference . It was due to me ignoring their advice and labels. It was due to us fighting like hell to get our kid back. What about the kids that don't have parents that do that? What about kids in foster care? What about the kids that are just looked at as behavior problem kids and disciplined for a medical condition happening that they can't control?? We CAN do better for our children and we HAVE TO! I insisted on strep testing and giving him antibiotics and finding a trained therapist in ERP for OCD. We paid for all of that therapy out of pocket and pulled the money from our son's college fund. We needed to get him through KG before we could even worry about college and I

figured we could put the money back in if we were blessed to get him back. Fast forward... Mason tested out of five college classes and is now a junior in college majoring in Spanish and marketing, has a girlfriend, loves to fish and hunt and workout, is a manager at the local restaurant he works at and is still a momma's boy and tells me he loves me every chance he gets! We had him back by first grade...and when the PANDAS reared its angry head in the coming years we knew what it was and we could treat quickly and get him right back on track.

I'm sure you will have many transcripts explaining PANDAS and PANS and the many triggers such as strep, gluten Intolerance, Lyme, coinfections of Lyme, hidden mold in the home, etc. because there are many types of triggers that can effect this autoimmune disorder. And once the autoimmune system is triggered to start fighting and is confused and starts attacking the brain and the brain is swollen at the basal ganglia .. havoc ensues because that's the part of the brain that controls mood and behavior. If we can understand this concept with rheumatic fever and the heart and strep...our medical community is certainly capable of understanding PANDAS/PANS!! And it's not a mystery that when other states, like Illinois, step up and pass similar legislature, the medical community "suddenly" gets it and starts taking care of kids ..and people from around the country start bringing their kids to those states!

But what about the others that can't travel? And can't pay the out of pocket for out of state? Our friends have had to travel to Tennessee, NYC and New Jersey and Florida to have their son get help and are thousands in debt! Some research says 1 in 200 kids get PANDAS/PANS. And other researchers say it's not that rare ..just rarely diagnosed correctly and their are many more suffering. I have personally helped countless people in PANDAS/PANS Facebook support groups and people in our community that have referred friends to me that have kids with recent autism or ADHD diagnoses or suspicions. I have explained it to as many therapists and people in the medical community that will listen to me. One example is a therapist acquaintance that had just gotten their doctorate in psychology 5 years ago. She had been a counselor for years but just had added to her initials. I saw her at a wedding shower and asked her how many PANDAS patients she had seen. She had never heard of PANDAS?! Seriously?? Just GRADUATED and not even a mention?! I explained what it was and her wheels started spinning. She said .."Oh my goodness, I think that is what this patient of mine has and im getting ready to diagnose her this week with tourettes because her parents are insisting on a diagnosis." I ordered her a couple books that i have bought for MANY and dropped them off. The next time I saw her she thanked me and said her knowledge has helped her truly help her clients heal.... and instead of slapping on lifeling labels and lifelong drugs .. she is helping them explore WHY. We need to ask WHY? And uncover the causes and treat appropriately.... so the hell goes away!

There are SO many cases in our country that kids were diagnosed with autism, bipolar , ADHD tourettes, schizophrenia... and once they found a brave practioner that places kids over money and they asked why and they found TRIGGERS ... The kids are being treated and those diagnoses have "disappeared?!" I thought those above mentioned weren't curable?? Many misdiagnoses going on!!! I'm glad there are brave researchers digging deep into conditions like schizophrenia and publishing research that links strep to it. I'm glad there are doctors not pretending PANDAS and PANS do not exist . I'm glad there are state representatives like yourselves that are willing to listen and learn and take the steps necessary to help OUR kids!!

I'll close with this ...

I did my social work field work years ago at Apple Creek Developmental Center..a state psychiatric residential housing complex that has since been shut down. Since the hell we went through with my son I have rethought alot of things. What's really going on with that kid misbehaving in the grocery store? Is anyone helping that teenager that posts about hearing voices? And I truly wonder how many of those poor souls that had been dropped off at Apple Creek by weary parents to spend their remaining days and years drugged and restrained actually needed a caring doctor to run some tests and find what was triggering their "schizophrenia" or their "hallucinations" , etc and to prescribe antibiotics or recommend mold remediation or other treatment that HEALS...vs STEALS life !

This CANNOT keep happening we have to do better. Thank YOU FOR DOING BETTER and ensuring that those that have promised to help WILL DO BETTER!!!

With much thanks and much concern,  
Mason's mom/ Laurie Beal

Ps. Thank you Mr. Young for all your hard work on this. I had multiple emails with your aide last year about this initiative and spoke at length with representative, Anthony Gonzalez when he requested a meeting with me. I'm glad to know we have people that care fighting for our kids!!