

Thank you, again, for hearing our story. At this time, we would like to switch to the topic of the cost of PANDAS, PANS, and AE illnesses.

The health, emotional, and financial tolls like what we endured in our story are why we are hoping for education for Kansas and local doctors, effective treatments, and early diagnoses to kids in Kansas with autoimmune illnesses affecting the brain and central nervous system, as well as hoping for a push for insurance companies to be required to pay for treatments. Obviously, early onset is extremely important. Just like with cancer or any other chronic illness, if you catch it early, you have much less severity to contain and much less damage to repair. So education is the first step in keeping the costs of these illnesses down.

The financial costs alone are demolishing families. Encephalitis illnesses have been nicknamed, the “rich person’s illness” – because your family has to be rich to survive it.

---

In 2018, Moleculera Labs sent out a survey to PANDAS, PANS, and AE parents, asking about the varying costs that hit their families during the years of illness. There were 57 questions on the survey, and 1100 people participated. Moleculera was kind enough to give us the results of the survey for the use of this hearing. They did, however, want us to say to you that these results are *not* yet published. A Harvard analytical team is going to do the official data analysis. Currently, this is for informational purposes only.

“Diagnosing and treating autoimmune encephalopathy (PANS/PANDAS) can be a very expensive proposition for families. It takes approximately 2.5 years from the onset of symptoms to diagnosis with only a portion of insurance carriers covering the costs for testing or treatment. Out of pocket costs for testing and treatment, along with associated costs for items such as the child’s educational expenses, mental health treatment for caregivers and other family members, and special diets can run into the tens, or in a few cases, hundreds of thousands of dollars. The financial strain is exacerbated when parents must leave their employment to care for their child full time or lose their job due to absences related to the care of their child. Parents have had to borrow from family and friends, deplete retirement and college savings, and in some cases declare bankruptcy or lose their homes.”

Ones I would like to add: people have had to take on extra jobs, go into debt, and do without necessities – sometimes even medical necessities.

1. “Although 96% of respondents reported having health insurance, only 42% indicated their insurance covered the therapies required to treat PANDAS.
2. Educational expenses ranged from tutors to homeschooling with 69% reporting costs ranging from 1-5K for homeschooling, and another 62% reporting spending between 1-5K for tutors and other education related expenses.
3. Family members also face a significant emotional cost when dealing with a child with this disorder. Seventy four percent (74%) of respondents report spending between \$1,000 and \$10,000 on mental health treatment for themselves or other family members. Another twenty-five percent (25%) spent between \$10,000 to more than \$25,000.

4. Forty-eight (48%) percent of respondents have spent between \$1,000 and \$10,000 for physical testing and other imaging costs. An additional 18% spent from \$10,000 to greater than \$50,000.
  5. Sixty-seven percent (67%) spent \$1,000 to \$10,000 for lab testing. Twenty percent spent from \$10,000 to greater than \$50,000 for testing.
  6. Medications/Supplements and Special Diets added another \$1000-\$10,000 to costs for 67% of parents and \$10,000-\$50,000 for 17% of parents.
  7. Seventy-five (75%) percent of parents spent up to \$10,000 out of pocket for doctor or other clinician visits
  8. Eighty-one percent of families spent up to \$5,000 for medical travel expenses
  9. Ninety percent of respondents spent up to \$10,000 to acquire neuro-psychiatric testing for their child(ren).
  10. 82% of parents of children who had a Cunningham Panel reported that it was helpful in getting a correct diagnosis (autoimmune disorder vs psychiatric disorder)
  11. 29% of patients have been hospitalized at least one time
  12. Average length of stay for all hospitalizations is 46 DAYS!!!! Median 14 days
  13. 53% of patients have between 1 and >12 MDs involved in their diagnosis and treatment
  14. Mean age of symptom onset 6.43 years N= 830, SD 3.32
  15. Mean age at diagnosis 9.17 years N=819, SD 3.45
  16. It was discovered that these families spend an average of \$193,000 out of pocket getting help for their kids."
- 

#### Categories of Expenditures and Losses:

- Alternative medicine and therapies like neuro feedback.
- Attorneys for drawing up protective paperwork when child turns 18, or special needs accounts, or disability.
- Brain scans.
- Changing schools. Paying for child to go to different school.
- Counseling for patient and whole family. Marital counseling, too.
- College expenses higher because child cannot perform academically and get scholarships, due to brain inflammation.
- Divorce expenses – this illness has taken a huge toll on so many marriages. Child support for special needs.
- Daycare for special needs.
- Defense attorneys when parents falsely accused of child injury or causing child's illness
- Detox, including infrared saunas.
- Educational advocates.
- Educational attorneys.
- Emergency room visits.
- Home schooling expenses.
- Genetic testing.
- Injury to others and those medical expenses.
- Insurance not paying for extremely expensive treatments, such as IVIG.
- Loss of income – Many times, parents are so overwhelmed by these illnesses that one of them has to quit a job, take less hours, take time off, or be seriously hindered in the movement of their careers. Getting laid off because you miss so much to help your child. Sometimes parent cannot work because of separation anxiety in the child or because the child is up all night in rages.
- Mold treatments for the house and medical appointments with mold specialists. Replacing items after losing everything to mold.

- More expensive food for controlled diets.
- Moving when renting and complaints are made about the rages. Moving closer to treating doctors.
- Out of network doctors.
- Psychologists.
- Private aid.
- Pull ups and extra laundry for urinating in sleep.
- Replacement and repair for damaged items – clothing, TVs, laptops, iPads, phones, computers, house damage, holes in walls, broken doors, broken windows, broken sinks, mirrors, furniture, lamps.
- Seminars and conferences to learn all we can.
- Supplements
- Testing, testing, testing.
- Tutoring.
- Travel for out-of-state specialists, including hotels.
- Truancy attorneys.
- Vacation time use for the illness.
- Vision therapy.
- Young adults with the illness needing financial support.

#### Categories of Expenses to the State:

- Educational assistance and special ed services that could be avoided if correct diagnosis and treatment could happen early.
- Family assistance
- Medical assistance, including hospitalizations
- Mental health assistance, usually not helpful when the immune system is the problem.

#### Our personal financial experience with these illnesses:

Costs for IVIG, plasmapheresis, and Rituximab vary from hospital to hospital, but for us, at the University of Missouri, they were approximately \$20,000 each. Brielle's last round of plasmapheresis at KU Med was \$47,000. In 2017 alone, our medical bills added up to **1.1 million dollars, and that was aside from anything we were paying out of pocket for alternative care, supplements, diet, travel, etc., which was a lot.**

- All in all, in 7 years, we spent or lost approximately \$700,000. That was for two kids. A mom from our group spoke last year that they spent \$400,000 on her one child with this illness.
- Bankruptcy
- 3 jobs – gone from the family
- Borrowed from parents
- Insurance: we have had good insurance and bad insurance throughout this journey. For example, in 2018, Brielle's plasmapheresis had been approved 100% before treatment, but after the treatment occurred, the insurance company refused to pay, and we have now been slapped with a \$47,000 bill. These illnesses were already financially disastrous and devastating to us, and continue to be so, unfortunately.

Compare the costs of early diagnosis vs late. Use us for an example. Kai and Brielle each.