

Leaving the Difficult Path of PANS Behind, Caleb (Boy age 7)

Says Robin, “My hairdresser had mentioned to me that her son had a rare illness, called PANDAS. It had been months earlier. I remember thinking at the time that it sounded like an excuse for bad behavior. But as we left Disneyland for home, I texted my hairdresser and asked if this onset sounded familiar. And, yes, it sounded familiar to PANDAS or PANS.”

Immediately she went to her pediatrician saying, “Something has changed my son like a light switch.” When she asked her doctor about PANDAS she said it didn’t sound like PANDAS and would not do a blood test for strep antibodies or mycoplasma antibodies as the hairdresser suggested. Instead, the doctor suggested psychiatric therapy – even though in front of the doctor her son was kicking the table and unable to control his movements.

For six months after this Caleb, now turning age 6, would go up and down in behaviors. A short list of how he changed: glimpses of normalcy and then back to outbursts of frustration, if things weren’t done “just right” he would get upset, sensory irritation to creases in socks or tags pants, intense separation anxiety, reading and writing difficulties where it once had been fine, and finally sudden, disruptive issues in school.

The pediatrician still was not able to help so her own adult medical practitioner read up on PANDAS and suggested to try ibuprofen only – and it seemed to help a lot. But Caleb was not out of the woods. The family found a functional medicine doctor who would do blood work and they found three issues: **lyme and mycoplasma and also a concern about multiple and persistent staph infections** in his nose and other parts of his body. By March 2019 they tried various pharmaceutical, vitamin, functional medicine supplements. It did have some modest affect.

Robin connected with research on the PANDAS Network website and the **work investigating the role of Th17 immune cells and their potential presence in adenoid and tonsil tissue**. A surgeon looked at the new research, and also the persistent staph and acknowledged that this can cause neurological issues. When the surgery was complete the tonsils were found to have deep scarring likely due to the staph. Now today, two months post tonsil and adenoid surgery, Robin and Jeff are seeing incremental improvement with Caleb overall and feel he is making steady gains.

The burden the family has now is what many new PANDAS/PANS families face; how to proceed with treatment and for how many months before trying something like IVIG or other prolonged treatment? Their doctor is willing to learn about IVIG and or other treatments and needs to seek advice from other experts. This new disease model is difficult on new treating physicians as well.

The other burden on the family is one of economics – the parents decided Robin would leave her outside employment to homeschool Caleb because they could see stress made his health issues worse. Despite the income cut which hasn’t been easy, the family has continued to make ends meet through prayer and a deep faith in God that this is the best path to allow Caleb’s body to heal.

EVEN IN THE MIDST OF A PANDEMIC OUR CHILDREN CAN THRIVE AND HEAL – We are grateful to the doctors and researchers who persist on our behalf.