

Daddy, Am I Going to Die? A True Story About PANDAS/PANS, And Unconditional Love... page 2

PANDAS/PANS is a little known, pediatric autoimmune illness that usually comes on suddenly (but not always) and attacks a child's brain causing all variety of mental health challenges including: OCD, anxiety, defiance, rage, verbal tics, and attention deficit...and can create many unusual physical problems, too, like: motor tics; bone, muscle, and joint pain; skin rashes; hot flashes; headaches; stomach aches; clothes sensitivities; and frequent urination, just to name a few.

PANDAS/PANS is triggered by the body's mishandling of infectious agents like strep (the biggest one), Lyme disease (another big one), and mycoplasma (also common), and sometimes environmental ones like black mold & harsh chemicals, and on occasion, even food allergies, too.

PANDAS/PANS is more understood and recognized today than it was in 2011, but still many pediatricians, psychiatrists, and neurologists know little to nothing about it, and insurance coverage is spotty and incomplete, even though recent studies estimate that 1 in 200 kids may have a form of this illness stealthily affecting their health.

So how is our story today?

Well I would say pretty darn good, but also not perfectly great.

Based on my participation in various PANDAS/PANS online support groups over the last many years, I would describe it this way... 80% of the community would probably be happy to be in our spot vs their current predicament, but I would also say there are 20% who are in a better final place than us.

Why is this?

Well our path has included the most recommended conventional treatments (antibiotics, ibuprofen, antihistamines, steroid bursts and IVIG)...and also nice "off-road" success via alternative treatments involving medicinal herbs and homeopathic medicines...as well as traditional CBT counseling.

Our situation is/was PANDAS/PANS/Lyme/Bartonella and I think this is a more complicated journey than "strep-only" PANDAS...or as I've heard some docs call it "PANDAS/PANDAS".

Also, add in some possible genetic/heredity tendencies in the family towards OCD and anxiety (on both grandparent sides). Don't really know, but perhaps the chances of 100% resolution become harder??

But I'm not complaining, as we have mostly prevented the life-crippling elements of this cruel condition, and my daughter lives a pretty normal life with a small group of close friends, participation in athletics and dance, attendance at summer camps and sleep-overs...pretty much the normal "growing-up" girl stuff even if a bit bumpy at times.

Today, our challenges involve teen self-image anxiety and school anxiety, wrapped up in a blanket of moderate OCD (that can sometimes flare intense, or occasionally be unnoticeably light, too). School work is a challenge, but given the right timelines & accommodations things usually get done, and grades are pretty good.

In business there is a concept the Japanese call "KAIZEN", which means taking small-step-actions to compel continuous improvement. That has been my approach to PANDAS/PANS...its often 2 steps forward, 1 step back...but over the long-term, consistently forward.

“KAIZEN baby, KAIZEN” is my PANDAS/PANS mantra...and let’s not forget, the need for a big dose of UNCONDITIONAL Love, too

So best wishes to you and yours on your journey as well. There is a path through, but you might take the wrong way at times, and find the need to course correct...remember its about KAIZEN.

Some resources I highly recommend for learning things, and/or pointing friends and family to, or for using with schools.

[National & International Advocacy, Education, and Medical Treatment News Groups:](#)

[Wonderful learning group about alternative treatment paths:](#)

[Excellent book by one of my specialists:](#)

[PANDAS: Reaching out - A natural and homeopathic approach](#)

[My favorite “quick-start” awareness book for family, friends, teachers, & coaches:](#)

[PANS / PANDAS Strength - Hope - Understanding: A Picture Book for Children, Family, & Educators](#)

[Powerful deep dive, social-proof book to give to school teachers and administrators:](#)

[PANDAS and PANS in School Settings](#)