

## Holly West's PANDAS Story (child testimony)

Ever since I was born, my mother thought I was different. I was always very quiet, and shy, but an extremely sweet, loving little girl. I can't remember at what age this started, but I remember having OCD symptoms, that were never diagnosed, but very obvious now. I remember I was deathly afraid of cigarettes. I thought I would die if I walked by someone who smoked. It got so bad that my mom had to actually buy a pack of cigarettes to break them apart to show me that they were not going to kill me; that seemed to help me a lot. I then had extreme compulsions, that I felt as though I needed to tell certain people that I cared about honest things that would make them feel bad. I would have to confess to people that they were fat, or ugly, and I would have horrible panic attacks through all of these OCD's. I had terrible separation anxiety, and couldn't go to school when I was supposed to. I started first grade when I was seven, school was always awful for me. I have social phobia, extreme anxiety and had learning disabilities. I had computer class in elementary school, and would not touch the computer because I believed I was going to break them. I had an IEP (individualized educational plan) for learning disabilities/ math processing, anxiety, and my mom wrote in so I would not have to use the computers. I had strep throat often, and had had scarlet fever.

When I was 14, I had extreme OCDS. They were horrific. It was like I was living in a nightmare that I couldn't wake up from. I had a sudden onset over night of suicidal and homicidal OCDs, and horrible insomnia. My mom brought me to the ER. They thought I was going through a mental breakdown, and sent me home. It got so severe that the hospital decided to admit me into a psychiatric hospital. This was the worst thing I ever had to go through my entire life. I was always an very shy sweet, loving girl, so these thought were polar opposite of anything I'd ever think about. It was like I was in jail. They removed my shoe laces from my shoes, I had to write with crayons, they gave me plastic silverware, as they did all these things they made my OCD thoughts worse. I got more ideas, and the fact that I was away from my mother with sick children made everything worse. The doctor I saw there noticed I had a cough, and wanted to test me for PANDAS, sure enough I had a positive strep test, and very high antibody level, he said it all made sense. The sudden onset, these obsessive thoughts, I was put on antibiotics, and three different psychiatric drugs, and was finally diagnosed correctly and was able to leave after 8 days. I was still not feeling better, I was then admitted to Boston Children's hospital. I had MRI's, spinal taps, tons of blood tests, strep test, titer test. I had doctors from all over the world, trying to help me. They all diagnosed me with PANDAS, I had an IVIG, a couple months later I felt so much better. I went totally off the psych meds.

My little sister was diagnosed with PANDAS at the age of four. She saw a doctor at Tufts Medical Center in Boston. I told the doctor I'm sure it was what I had. After five years of feeling okay, I got another PANDAS episode. I started seeing the same doctor with my sister, I was put back on psych meds, and antibiotics, I only felt slightly better, I wanted an IVIG, but he said they were too costly. He diagnosed me with autism at twenty years old (PDD NOS) and my little sister with asbergers. My little sister who is now eight is still suffering greatly. Our whole family decided we wanted to move out of New England to somewhere warmer with sunshine to help us, like Florida, because Taylor and I were constantly depressed. After we moved, I had another episode. I saw awful doctor's in Florida, that of course never even heard of it, treated me again with psych drugs. I am twenty two now, I still struggle with PANDAS. I'm seeing a new Doctor soon in Florida, who believes in PANDAS, and knows how hard of a struggle it is. I have been suffering for

almost my entire life. I have been unable to go to college, or work because of how sick I've been. My little sister who is now eight is still suffering greatly. She is home-schooled, and extremely depressed. We need more awareness. How many like the thousands of children diagnosed are misdiagnosed? and left untreated. Please spread awareness, and help save lives. This is just a short story of what I've been through, it's ongoing and probably will be until PANDAS gets more awareness. Thank you for reading.

Jene Hicks, PANDAS parent

To whom it may concern,

I am very disappointed that I cannot be there to support my story. I do believe all participates in this conference have the similar stories to tell.

It was September 11, 2010, my son Joseph was 12 years old when I noticed this change in behavior. It was horrifying to see this happen to such an extraordinary child. Joe is so outgoing, kind, energetic, and loves to talk, but at this time he was not. He was frightened to leave the house. He feared people and did not want to go to school. After a week or two of this, Joe went into rages. He could not control himself, he could not stop moving, his body would not rest. After several weeks Joe starting with tics. He would make sounds and move his head back and forth, it looked as if he was autistic. At this time I know this was not my child anymore and I needed answers. I decided to go straight to the emergency room at Long Island Jewish Hospital, still no answers.

This scared me.

He was then released, and we still did not have a clue to what was happening to him. Joe was bed stricken for two weeks with sever body pain. He could not walk or talk.

After several trips to Joe's pediatrician and no indication as to what was wrong, I searched the web and found two very special doctors, Dr. Bouboulos, and Dr. Trifiletti. It was only then that I was told my son has PANDAS.

As of today, Joe is doing wonderful. He has had eight(8) IVIG treatments along with antibiotics. I see a 95% recovery and will continue to trust Dr. Bouboulos in his full recovery. I am hoping my next email will be my final notice to all that my son has fully recovered from this nightmare.

I hope and pray, all of you have this same story.

GOD BLESS!

**BEST REGARDS,**

*Jene Hinks*

Jim and Terri Masar, PANDAS Parents

To Whom It May Concern:

Our son Mitchell (age 15) has suffered with PANDAS for the past three years. His symptoms include OCD behaviors including tapping, facial ticks, non-stop talking (often offensive and profane) and extreme insecurities revolving around his perceptions of being lied to by his parents and by any authority figures. Mitchell has been diagnosed with Lyme Disease as being at the root of his PANDAS problems. We have an appointment with a Lyme specialist at the beginning of March 2013 and are hoping for the best. However, "hoping" is a term that we as parents are all too familiar with. We began our search for help with local doctors in the Akron, Ohio area, who despite their good intentions, were inexperienced in dealing with the complexities of the PANDAS condition. Upon advice from the PANDAS Network's Lynn Johnson, we made contact with a Connecticut-based doctor who is an expert on the treatment of PANDAS. It was this doctor who, after eliminating other PANDAS causes, diagnosed Mitchell with Lyme Disease, which brings us now to our current wait (which began three months ago) for our appointment with the Connecticut-based Lyme specialist.

Additional PANDAS research and funding for PANDAS research are absolutely needed as the PANDAS illness brings absolute devastation to the PANDAS sufferer as well as to the PANDAS-afflicted family. The relentless stress and disruption inflicted on the normal every-day aspects of the family plagued with PANDAS is something that is quite beyond the non-afflicted family member's ability to imagine. I can best describe the effects of PANDAS on a family, in terms of the family members being forced to constantly focus on insanity, while at the same time knowing that the child with PANDAS is not insane, but afflicted with a terrible mental condition that in many cases has been controlled and even cured. However, it is as if the family must wait in line until the proper diagnosis and treatment is discerned for that specific family member's PANDAS condition. Also, the schooling of the child suffering with PANDAS is (at best) disrupted, and (at worst) virtually eliminated.

Please, for the sake of the child afflicted with PANDAS, for the child's siblings and for the family as a whole, my wife and I request that legislation be brought to bear on increasing PANDAS research and increasing funding for this devastating emotional condition. Please, on behalf of PANDAS families everywhere in America, we ask for your help.

Sincerely,

Jim and Terri Masar

Joy Drinnon, PANDAS Parent

My son, Collin, suffered from chronic sinus, ENT, and strep all through preschool years. Had tonsils out at age 7 but still got strep AGAIN in August 2008 when he was 8 years old. Developed severe enough head tic by that October that he was tested for seizures (didn't help that a CT scan came up with a "shadow" that alarmed the pediatrician). Hospitalization for tics and brain scans yielded normal scans (shadow was just a shadow and not a tumor, thank goodness). He had attention problems, emotional lability, night-time anxiety, frequent urination and mild OCD at the same time. Pediatrician tested his ASOtiters, which were high and put him on antibiotics. We were sent to neurologist but he said he didn't believe in PANDAS, dismissed the other symptoms he presented with as coincidence and we never went back to him. His tics went into remission eventually but do come back from time to time during flare-ups. Multiple flare-ups since but none definitively linked to strep because he doesn't come up positive. Pediatrician didn't want to keep running blood work every time he had symptoms so they tired of us coming in with all our weird symptoms that sounded very "psychological" to them after each negative strep screen. Tried being on prophylactic antibiotics but they didn't seem to reduce symptoms consistently so we reluctantly went off. Been battling 2-3 flare-ups per year ever since. All the same symptoms as before but milder tics and more OCD. Still trying to get pediatricians and other doctors to really treat the whole package of symptoms instead of isolating each as a separate issue. Even though our pediatrician group knew he had PANDAS they still treated only the most severe complaint each time we came in, so we have prescriptions for ADHD, frequent urination, sleep problems, stomach cramping, and plenty of referrals for the OCD, anxiety, and depression. Even though these are all coming together during flare-ups they are treated as isolated issues. I think most parents can attest to the wide spectrum of doctors they have been referred to. He is currently a 13 year old boy who only weighs 80 lbs because he is scared to eat and is chronically tired from poor sleep due to OCD/anxiety. I am hopeful that by spring he will back to the relatively healthy boy that I had in the fall but we have no treatment on the horizon to help him get there sooner.

Joy (mother of Collin)

## Kristine Gleason, PANDAS Parent

My name is Kristine Gleason. I have two possible PANDAS/PANS children. I say possible because there is a desperate need for more research and doctors to treat the many children suffering. My son Daniel, we believe, had his first exacerbation at the age of seven after being sick with possible strep or a virus. He was a carefree, outgoing child who was debilitated by separation anxiety and generalized anxiety that left him unable to leave the house to go to school, the store, or a friend's house without violently throwing up with diarrhea. It was short lived, about three months.

April 21, 2011 is a day we will never forget. Daniel had been sick with what seemed to be the flu and had just been to the pediatrician for his eleven year physical where he received a D-TAP vaccine. Within a few days of being sick and receiving the vaccine, like the flip of a switch, Daniel became a child we had never seen before. He was crippled with OCD and severe intrusive thoughts that literally came out of nowhere. Scared as we had never experienced anything this severe, I took Daniel to the Albany Medical Center Emergency Room. Because of the nature of the thoughts, we were told he would be transferred to an adult mental health facility to spend the night and be transferred the next day to the first facility to answer a fax. I was told he may be going to a facility out of town or state, and I would not be able to accompany him. It was at this point that I knew I had lost my son to the mental health system of New York. During a two week stay at a mental health facility in Saratoga, NY, Daniel was put on anti-psychotic medications that made the thoughts magnify. It took several psychiatrist changes to eventually get Daniel off all anti-psychotic drugs. He was portrayed as a manipulating, troublesome child, and I was told I needed to give the drugs a chance. I had always heard nothing but wonderful comments from his teachers about how he cares for others and always does the right thing, and I had lived with this child for 11 years of his life, and this was not the child the professionals were telling me they saw. I vowed the day I picked him up from the mental health facility that he would NEVER have to go back.

Through research and a phone call from the executive director of the PANDAS Resource Network, I was able to find a doctor to help my son. Long term antibiotic therapy helped Daniel. Today he is ninety-eight percent back to the child who loved school, was outgoing, and told me not to "sweat the small stuff." Without antibiotic therapy and a doctor who really listened to our story and symptoms, I believe Daniel would be lost to the mental health system where many times they are quick to prescribe anti-psychotic medications.

My daughter Grace, I believe, suffers from PANDAS/PANS as well. Her symptoms are less severe than her brother Daniel and antibiotic and steroid therapy has helped her as well. I have dedicated my life to fighting for these children to receive proper diagnosis and treatment. I will not stop the fight until parents are not afraid to approach doctors to find help and healing for their children.



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On January 13, 2011 my daughter Lily, tested positive for strep. I remember this day so vividly because the Strep bacteria was already my sworn enemy. I know from experience that Strep can rob me of my children. Lily's older brother, Charlie, has PANDAS, and had had his first, and what we thought was hopefully his ONLY, replacement of immunoglobulins (IVIG), the month before. We were working tirelessly to keep him healthy so that his IVIG could work its magic and allow him to heal. Her other brother, Max, had also fought chronic respiratory infections, strep, asthma and allergies, sensory processing deficits, and OCD since he was two, although no doctor would ever put a label on his experience because he was lucky enough to return to a functional level periodically. That winter day Lily had a sore throat, had been up sleepwalking, and had a mild fever. So I swabbed her. I had purchased strep tests to have at home for just this kind of dreaded occasion. This pattern happened all too frequently to us. When I saw that first line appear through the little window, I just about died. How could this happen? We had been so careful.

Lily held on to that strep infection for months. She'd take her two weeks of antibiotics, and within three days she would test positive again. More antibiotics. Strep again. Different antibiotics. Charlie went on a roller coaster ride with his antibiotics too. We'd increase his dose when we knew Lily was sick, and taper back down to his prophylactic dose, and then go right back up again. All of us had various other viruses and infections that winter and spring. We just couldn't escape it. Amazingly enough, Charlie became our "disease detector." When someone in the family was exposed to anything, Charlie's large motor tics and OCD would increase. His reactions were warning us that an illness was coming. And he was right 100% of the time! Within a day or two, someone would be hacking up a lung.

By late April/early May, I had learned to recognize that Lily was sick by her fearful sleep talking/sleepwalking activity exactly 45 minutes after she had gone to bed. After four two week courses, and one month long course of antibiotics, I thought Lily was finally done with the relentless strep infections. And then I saw it. She was shrugging her shoulders in an unusual way, all the time. She'd roll her neck and say things to me like, "Mom, I can't seem to stop doing this," and, "It feels better when I do it, but then I just have to do it again." She was also unable to leave my side for any length of time when we were at home. She couldn't be in the family room while I was in the kitchen, or God forbid I'd ask her to go get dressed upstairs while I remained downstairs. In the day light. With her brother upstairs. Never. She was 10 years old! But this was something she had been comfortable doing for a few years already. She would require me to be in the master bedroom while she took a shower in the master bath. She refused to shower in the hall bathroom any longer because it was dirty. I would have to stay right there, and if I was caught leaving (had to do this on occasion for various mom reasons), she would absolutely panic. Lily was also having some social issues. She had suddenly begun to view her friends suspiciously. She misread situations believing if a friend gave her a silly look or said something negative, then that friend must HATE her. She began talking to me about her enemies. This was a very well liked kid! I couldn't possibly understand how her friends could do this to her. I would discuss it with her teacher, and she would tell me that nothing like that was going on to her knowledge, but that she would check in with Lily periodically. By this time, it was the very end of her 4th grade year. Looking back on it, neither her teacher or I could place our finger on what was happening to Lily at the time, but we knew something strange was going on because both at home and at school we were having to treat her with kid gloves; constantly adjusting things to ensure that everything was right in her world.

Lily began not wanting to go to birthday parties, and occasionally asked me to make up something for her to do so she could say she “couldn’t” go to a friend’s house when invited. I understood that she didn’t always want to be social, because of her anxiety over her friends HATING her. But the more I did it, the more I realized that no one hated her AND could possibly be inviting her to this many things. When I discussed that with her, she admitted to me that she knew no one hated her, she just “believed” they did. She knew it was irrational, but did it anyway!?

At the very end of the school year normal standardized test results came back stating that she did not qualify for gifted and talented services from the school district. She is an extremely bright child, and along with her teacher, we thought for sure she would be eligible. She missed it by just a point. Her teacher did everything she could to convince the powers that be to accept her based on classroom performance and not only the test scores, but it did not work. This was absolutely devastating for Lily. She cried for days. The jealousy that she displayed towards her friends who were in the program was downright ugly. She raged. She tantrumed on the floor kicking and screaming like a three year old. This was just not her. We did not know who she had become. Where had my little girl gone?

I mentioned all these things to Dr. K, but she was always a totally charming kid in his office. He wanted to wait and watch. He was very aware that her lymph nodes were frequently the size of walnuts on both sides of her throat. But Charlie was also very sick with a sinus infection and his rheumatoid factors and immune complexes were through the roof. His joints were swelling and he was exhausted all the time. We needed to concentrate on him.

Throughout the summer things just remained on the border of strange for Lily. She only saw the friends who lived very close by, who are almost like extended family, and that minimized the social

issues she was having. She also didn't have to think of academics for awhile. Phew! But she still was having severe issues with staying home when her dad and I went out. She would call us in a hysterical state begging for us to come home immediately. She thought that if we were five minutes late that something might have happened to us. Her brother couldn't help her because she wouldn't allow him to, and even when we got home it would take an hour to calmly discuss with her that she had been safe; that we were safe, that we would never leave her in her older brother's care if we felt he wasn't responsible. And then one of us would have to stay there rubbing her back and reassuring her until she fell asleep. By the end of summer, her neck rolling tic began to really bother her. She had muscle aches and headaches constantly. She had found a way to make it look as though she could "do the wave" with her shoulders, and then jut her chin out like the funky chicken; she was dancing to hide the tic!

By August she was excited to get back to school. When it started she seemed to really calm her emotionality down. She loved the new teacher she got, and this teacher knew

of her disappointment and anxiety regarding the gifted and talented program. She seemed to have a soft spot for Lily, and promised to give Lily work that would consistently challenge her. Lily ate that kind of attention up. She was still rolling her neck and had begun stretching her legs out quite a bit, but I thought it was a great start to the year. She seemed happy.

The month of September passed quickly for Lily. She was voted onto Student Council and she had decided to participate in a local production of Beauty and the Beast. She was cast as Lumiere, the Candleabra. She also had some teeth removed to make way for her braces on in mid-September. She was placed on penicillin to ward off infection and ibuprofen for pain post surgery. She

seemed to handle it all very well. Her neck rolling decreased initially, but within a week post oral surgery she began to complain of sore throats, stomach aches, and headaches, even while on the penicillin. She was rolling her neck and shrugging her shoulders incessantly. Her brother, Charlie, was also exhibiting increased ticcing at this time. But I could tell he was getting sick. Lily began to show symptoms of serious anxiety. Her surgeon knew this was a risk for Lily, so to be safe he increased the penicillin again. Her anxiety was strange. She would be hyper at bedtime, and cry that she couldn't sleep. So she would stay up to write stories. And then HAVE to read them to us. She declined her part in the play as Lumiere, insisting that she couldn't do it (she'd already been practicing it, had memorized her lines, and was doing great!) She loved her play! This was such a surprise for all of us. She was constantly fretting and worrying. She began to follow me around the house again, like RIGHT BEHIND ME. I would sometimes trip over her! She would only shower in our bathroom again, and if I forced the issue she would refuse to shower at all. She would never wash her hair. She was crying frequently, and even had a major panic attack when my husband and I needed to be out of the house for a meeting at her brother's school. She called us over and over again to come home. She was scared someone was breaking into the house. I took her into Dr. K's office, explained what was happening, and he felt she had contracted another infection while on the penicillin. He switched her over to augmentin. In early November, she had an ear infection and joint pains in her hips, as well as what she described as "zings" of pain in her lower back. She stayed on augmentin for a full six weeks. Her anxiety symptoms did eventually get a little better. For example, she felt free to walk around our home on her own! But that was really the only significant change we saw in her. She continued to pick bizarre fights with people in the family. She would argue about things that just didn't matter. She always had to have the last word. She would be fixated on what was "right"

and whether or not she was “right” in a particular situation. She would be downright rude when talking to others. She began eliminating foods from her diet. All of a sudden foods she had loved (ex. eggs, oatmeal, fruits) she would no longer eat. When she didn’t get her way, she would sulk, and stomp, and cry like a much younger child. It was weird. All of these behaviors were just not like her. But we were kind of just getting used to her. She seemed unhappy most of the time.

On November 28th, Lily had her last dose of augmentin. By November 30th, she came home from school reporting that her neck rolling had been a problem and that she had accidentally kicked the boy across from her because her leg was jerking and she HAD to stretch it out over and over again. The next day, she came home and sat on the floor and rolled her whole body around and around in circles. She said she had been holding it back at school, so she had to do it at home. It took her 10 minutes to feel alright enough to stop. She said her head was killing her because of that movement. I gave her some ibuprofen for her headache and she slept for twelve hours. The next day she fell apart while on a field trip at school. Luckily I was there, and was able to get her out of the store (they were at Target shopping for a needy family charity project). But her teacher finally saw the beginnings of her emotional breakdown. It was all because Lily had forgotten her homework at school before they left for the field trip. She was mortifyingly embarrassed that her teacher, being very kind, offered to bring it to our house after the field trip. She apologized over and over for forgetting it. She was calling herself stupid, and was just completely unable to let it go. She wasn’t in any trouble. And it was pretty easily fixable, but in her mind, it was a catastrophe. I almost had to carry her out of the store.

The next day I contacted Dr K with my concerns. He stated the obvious. She needed IVIG to get better. We had attempted for

preapproval and appealed for coverage after Charlie's IVIG the year prior with no luck. Our insurance company felt it wasn't deemed necessary and that IVIG was considered experimental. Their eyes were closed to pain that my children were suffering. Every day they were getting sicker and sicker, and I felt desperate. I began writing appeal letter after appeal letter, totaling seven letters for the two children. Only twice did I even get a response from them. I got my husband's company involved. We met with their insurance broker to no avail. But the last response hit me square in the jaw. The doctor who had reviewed our appeals asked me why no one had ever told me of the severity of my children's immune deficiencies. Of course I knew PANDAS was an autoimmune response, but no one had ever explained to me that they didn't have the ability to make antibodies at all. The hint was received loud and clear. I needed an immunologist, and fast.

In the spring of 2012 we began to travel to Connecticut to see Dr. Bouboulis. He trended the bloodwork of the entire family to see what we were truly facing. He placed us ALL on antibiotics to ensure that anything any of us held would no longer get the better of the kids. Immediately we all began to see a positive change clinically. Moods were better, headaches resolved, OCD was minimized. We watched and waited for more positives, but ultimately what we found was that the children all had Secondary Immune Deficiency Disorder as a result of PANS, with Specific Antibody Disorder and Chronic Sino-Respiratory Infections. It is a mouthful to say, but it describes succinctly what I had been fighting for with all three of my children for the last thirteen years. I had repeatedly gone to our pediatricians and asked why my kids were always sick. Even though I would say it outright and in jest when we left the office, "See ya in two weeks or sooner!" not one of our team of esteemed doctors ever picked up on it. All three of my children always looked so pale and sickly, and so often had

strep, bronchiolitis, walking pneumonia, ear infections, unexplained rashes, and sinus infections. Even though we are now on the right path towards healing, I am resentful for being ignored, and so often belittled for my worries. The signs were there, clear as day, but those doctors wouldn't listen to my pleas for help.



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February 24, 2013

This is my daughter, Lily. She is 7-1/2 years old. She has had PANDAS (Pediatric Autoimmune Neuro-psychiatric Disorder Associated with Streptococcus) since she was 5 years old.

Lily was a happy child the summer before she began kindergarten. After two weeks I received a phone call from her teacher, advising me that Lily was aggressive with other children, was unable to sit for instruction, and was defiant with her teachers. Lily had not behaved this way in Pre-school. Over the next two months Lily's behavior and mood was unpredictable. She could not concentrate. She had to smell everything. She was compulsive. She had separation anxiety. She was unable to sleep. She continued to be ill, and we'd find she had 'another' strep infection again and again. I thought it was a tough season for strep. By mid-December Lily struggled to attend school more than 3 days per week. Several weeks later, Lily had an anxiety attack in class. That afternoon, while speaking with her pediatrician, was the first time I heard of PANDAS. I am forever grateful that he had knowledge of PANDAS, however, he is not an expert in the field, and his treatment plan did not help Lily.

At school, she was placed on a behavior plan, which demoralized her and shook her self-esteem. It measured her behavior based on compliance--something that a child with PANDAS cannot self-control. Other children had labeled her as a kid not to play with at recess. Lily hated school. Her life became her personal burden as it did to our family as we struggled to understand what PANDAS was, how to find someone in the medical profession who knew how to cure it, how to address her needs at school, and how to explain it to the adults and kids we interact with.

Lily does not have the strength and stamina to participate physically or behaviorally at age appropriate expectations in activities she has tried, such as basketball, soccer, dancing, karate and music lessons. This further affects her self-esteem as well as increases the separation between herself and her classmates. We decreased involvement with other families, to the point of eventual withdrawal from many gatherings. Our family was invaded and paralyzed by PANDAS. Lily has an older brother who felt neglected as his sister consumed parental attention. Thus, our family's stress level increased when this translated into behavior problems from him.

After a year and a half Lily's pediatrician felt she should have recovered from PANDAS, if indeed she had it. He then diagnosed her with obsessive-compulsive disorder (OCD) - a mental illness. We knew OCD did not develop overnight, with sudden onset. Yet, we had no other medical advice in support of other possibilities. We could not find another pediatrician who could converse about PANDAS, never mind opine. Lily displayed ALL of the symptoms of PANDAS. We refused to accept an OCD diagnosis for her.

We learned of a PANDAS specialist and waited six months for an appointment with Dr. Denis Bouboulis. He was knowledgeable about PANDAS! He had a treatment plan for Lily. For 1-1/2 years Lily was improperly diagnosed and treated, and as a result suffered both physically and emotionally.

Lily is still under the care of Dr. Bouboulis, and her battle with PANDAS is far from over. She continues with consistent trending of being symptom free for longer periods of time. She still suffers regressions and flares when exposed to triggers.

I am sharing Lily's story in hopes that other children and their parents should not have to experience what we have as regards to obtaining correct medical diagnosis and treatment for PANDAS in a timely manner. I feel strongly that there should be PANDAS education to all physicians in every specialty for better understanding, diagnosis and thus proper treatment. There needs to be research into the disease itself. I also feel very strongly that every staff member in every school district needs to be educated concerning PANDAS; what it is and how to best support a child who has PANDAS to succeed in school.

## **Our Family's Experience with PANDAS**

My name is Sam Haber and I am here with my wife, Lynn Haber, to tell about the impact PANDAS has had on our family. Lynn is a board member of PANDAS Resource Network, and she worked as a teacher education professor at Southern Connecticut State University before becoming a stay-at-home mom. I am a third grade teacher in Newtown. We have two teenage sons, and we live in Trumbull. Our older son Gary was once a high-achieving student who won writing awards, had many friends and numerous creative and academic interests. He had a zest for life and a thirst for knowledge; knew the alphabet at 18 months, comprehended fourth grade level multiplication as a first grader, became an avid reader, and was considered a role model by his teachers. His second grade teacher began the parent-teacher conference with, "Your son is a joy to have as a student. I wish I had 25 Garys in my class!" These kinds of comments were typical of every conference throughout Gary's years in elementary school.

All of this changed when Gary contracted a strep throat during the winter of his fifth grade year. Within a couple of weeks, he was complaining of curse words and other thoughts that were stuck in his head. We brought Gary to an OCD therapist, who believed he could have PANDAS, but told us if this were the case the OCD would get better with time. But several months after the strep, two vaccines that were given during his 11-year-old checkup exacerbated his OCD and caused new and debilitating symptoms. Gary would become unresponsive and stare blankly into space for minutes at a time. In addition to these "trances," Gary developed severe motor tics, hyperactivity, and insomnia, and he was unable to have normal conversations with people.

We began our long medical journey, going from doctor to doctor, getting numerous tests and trying to figure out what was wrong. One neurologist prescribed SSRI medication which ended up exacerbating Gary's symptoms and causing impulsive, reckless behavior. We later found out that in cases of PANDAS, SSRIs don't address the underlying causes and often make matters much worse. Multiple doctors and psychiatric hospitalizations followed. A Yale psychiatrist and Tourettes expert diagnosed PANDAS and acknowledged the role that vaccines can play in exacerbating this autoimmune condition. Gary was admitted to Yale for extensive testing. Yale referred us to a doctor at Children's Hospital of Philadelphia, who did plasmapheresis which began the healing process.

Over the next two years, we saw neurologists, psychiatrists, immunologists, integrative doctors as well as Lyme doctors since he had tested positive for Lyme, and these doctors believed that Lyme, in addition to strep, was an infectious trigger contributing to his psychiatric symptoms. There were numerous medical interventions and alternative treatments, and we saw great improvements over time.

Shortly after he finished his plasmapheresis treatments in the summer of 2008, he started seventh grade and was able to attend school for a full day instead of just a few hours. He made attempts to do homework, and some of his creative interests started to come back. Slowly we began to see glimpses of the boy we knew, and with intensive tutoring, he was able to have his BarMitzvah.

Over the next year, we saw more improvements, which were the result of additional medical interventions including IVIG treatments. When Gary graduated from 8th grade he was the recipient of the Rotary Club Award for Extraordinary Progress. That year he developed a website for kids to educate them about PANDAS, and he also wrote a personal essay about his struggles, which he titled "I've Come a Long Way." He was about 80% better.

But we didn't know at that time what a long way he would fall. In the summer following his eighth grade graduation, Gary fractured his arm at camp and this triggered a major setback with his PANDAS. Symptoms continued to worsen after a growth spurt. By the spring of 2011 Gary began to suffer from delusions and in spite of many types of interventions including PANDAS and Lyme treatments and the addition of antipsychotic medication, Gary's mental state deteriorated. By the time he entered tenth grade, he was hearing voices. He became a danger to himself, and we hospitalized him at St. Raphael in New Haven. Psychiatrists there began to try higher doses of antipsychotics but nothing helped. His case was accepted for voluntary services with DCF; he received Medicaid and was transferred to Riverview, the state psychiatric hospital for children.

Gary still resides at Riverview. He is completely disabled with auditory hallucinations and is unable to function outside of a hospital. He spends his days pacing and talking to himself. He cannot read, write, draw, play games, do school work, or engage in normal conversations. For over a year now he has been on Clozaril which is considered the last resort and most effective medication for schizophrenia, but he remains severely impaired. The psychiatrists there are caring and conscientious, but they lack training and experience with PANDAS. Over the last few months we have made progress in getting his doctors to begin to see that what is going on with Gary is atypical and that he is not likely to respond to conventional psychotropic drug treatment for schizophrenia. His doctors are now trying high doses of antibiotics, and we are hoping to find a way to get the doctors on board with regular IVIG and other less conventional treatments. Doctors must be educated to recognize PANDAS and distinguish it from other psychiatric illnesses. For a moment please imagine yourselves in our place as parents. What would you do if a simple bacterial infection set off an antibody reaction that acted like an assault weapon on your child's brain, taking away his or her ability to function in a normal way? What would you want from your child's doctors, your insurance companies, and your state legislatures? We ask that you take action against this disorder by not only requiring insurance coverage but by raising awareness, through more research and education. We agree that an act concerning PANDAS needs to include the establishment of a panel of experts to

assist in the development of practice guidelines and the establishment of a state liaison to communicate with the NIMH and the CDC, but we also believe that the experts from this panel need to educate psychiatrists in our own state, especially those working with patients in hospital settings. Imagine how cost saving it would be for Connecticut if state hospital psychiatrists were trained to recognize the signs of PANDAS and follow a standard protocol of guidelines for testing and treatment. In the long run, legislation that allows effective communication between experts and those caring for our children in hospitals would save a lot of money for the state and much heartache for families.

We know we have a long road ahead of us, but we remain hopeful that with the right kind of treatments our son will heal. We will never give up on our son and will continue to advocate for him, just as you would do for your child.

Melinda Boutsikakis, PANDAS Parent

Thank you for giving me the opportunity to provide our story about PANDAS. I believe it is extremely important especially after our experience.

Our family had an interesting few years plagued by Strep. It began with my youngest son, Michael, being a strep carrier. Obviously, unaware, I myself who hadn't had strep in 20 years had strep five times in six months; my daughter had strep three times and my other son, Thomas, also had strep 3 times. Michael never had a symptom and so we hadn't had him tested. Finally, I asked, Is it in my house?, could my dog have it? where is it coming from? The pediatrician tested my son Michael and he tested positive. After a course of antibiotics, still positive and after an additional course of antibiotics, still tested positive. The only solution having his tonsils removed, which we did. My biggest frustration during this process was that the doctor said carriers don't pass the virus on so it isn't possible that Michael is giving your family strep. Well if the American Pediatrics say it isn't possible, it must not be right? Well, since Michael had his tonsils removed I have never had strep again and it was two years before it reared its ugly head in my house again.

I noticed my son, Thomas, had been blinking a lot. I used drops on his eyes, I asked him to stop, we tried allergy meds, and he had no relief of the blinking. Thomas said he had no control over it, he couldn't help it. I was annoyed because looking at him blinking all the time was disturbing. My friend mentioned that it looked like a tick, try Magnesium. I did but it didn't help. After about 8 weeks of working on getting rid of this tick at home, I took him to the doctor. I mention the 8 weeks not to say that I am a bad mother, I am not, but to let you know that I also don't over react. I made sure that there wasn't anything in his eyes, I talked to him about it, I read about ticks, I tried everything suggested to eliminate a tick, I even tried to ignore it to see if he was doing it on purpose. Then I took him to the doctor. I went to one of the pediatricians in the practice we use, but not Thomas' normal doctor. She looked him over and sweetly said, "I know this is going to sound funny, but there is some research to suggest that a tick of this nature could be related to Strep, is it okay if I test him?" While my mouth said "of course," my brain started spinning. Strep again, no sore throat, no fever, no stomach ache, no smelly breath, here we go again.

Minutes later, the doctor came back into the room and confirmed strep. Thomas was put on antibiotics and my world was set right again, or so I thought. This was the beginning of a year long battle and I mean battle. Battle with doctors, schools and even in our home. The 14 day typical treatment for Strep worked great, within two days my son's tick was gone. Things I hadn't even noticed changed too, I was so hung up and annoyed with his tick that I hadn't really noticed his behavior until that changed too. Thomas, wasn't on edge anymore. Once on the antibiotics he was no longer emotional about everything, he wasn't slamming his fist or crying when he was doing his homework. I no longer saw him looking at his homework with his head laying on the table. He wasn't as frustrated with his siblings. He was "normal" again. I was thrilled.

Then on day 16, yes two days after the antibiotics course was over the tick was back and now more notably was the behavior I hadn't noticed before. I called the doctor and the

said the antibiotics still work for a few more days so they couldn't test him again for strep for a few more days. So I make the appointment and wait.

Tick, Tick, Tick.... The day arrived and we went back to the doctor, we were able to get in with Thomas' regular pediatrician. He took in the information, scoffed at it and tested him for strep. Thomas' test came back positive. The doctor said that there is no connection between the tick and strep. I took the prescription and left. Two days back on the antibiotics the tick was gone.

I am not going to drag my letter on for the year that I went through this. The pattern continued on the antibiotic the symptoms disappeared off the antibiotics the tick and behavior returned.

I want to explain the struggle with the schools, the school work and the doctors before I conclude.

Through out this ordeal, Thomas' school work really started to slide. His hand writing became illegible. Thomas went from A's in the accelerated math group, he was doing 7th grade math in 5th grade, to F's he couldn't even add simple numbers. The worst part is watching your kids, who knows he should be able to do it, become frustrated and cry because he can't. It is awful as a parent to sit down and review instructions or explain how to do a problem have him say "oh yeah" walk away and have him stare at the paper confused. Or read a paper and have the handwriting look like a stroke victim. Keep in mind, I had never heard of PANDAS, I had no idea why this was happening.

I called our doctor and met with him countless times, I was always made to feel like I was over reacting, like I was crazy. I wondered if I was crazy. I talked to his teacher, I felt like I was crazy. I saw the pattern, I am the mother, I was clear that there was a problem I didn't know what the problem was but I knew there was a problem and everyone made me feel crazy. But at the end of the day I looked at my boy and he wasn't my boy. He was in overdrive. If there was a fly in the house he would run screaming to his room close the door and push furniture up against the door. He wasn't my kids anymore. The doctor started talking to me about accepting that my kids had turrets.

I started research myself, and came across PANDAS. I finally felt like I figured out what was wrong. I took my information to the doctors and they looked at me like I was crazy. PANDAS is for people looking for a problem. I have trouble expressing in writing the experience we had. At the end of the day our saga lasted a year. The result in his schooling is that he missed an entire year of math and had to retake the year. His national test scores went from the 99% to the 45th and once over were much higher at 86% but clearly lost ground.

He ultimately had to have his tonsils and adenoids removed, doctor's were surprised at how large and infected they were. The doctor said while not visible just looking in the throat the tonsils had grown

**To whom it may concern:**

**My son Drew was a healthy, athletic, social, and fun loving 6 year old boy who suffered with mild anxiety.**

**Just over a year ago he changed over night and has not been the same since. Our entire lives revolve around him and the devastating effects PANDAS has had on our family. Drew has awful intrusive thoughts that have taken over his life, as well as suffering from tics and SEVERE separation anxiety. His fears and thoughts consist of death, fire, being left alone, the opposite sex, differences in people, you name it.**

**His tics include, eye blinking, snapping, clearing his throat and sometimes odd movements with his neck.**

**The separation anxiety has taken such a toll on our lives, that he will no longer attend school and has to know where I am at all times, not allowing me to be able to return to work. At this time,**

**I am having to leave my job, leaving us with no second income and more medical bills than ever!**

**We are currently working with Dr. Bouboulis, where we are on our third antibiotic and second set of lab work, now including my husband and I as well.**

**Drew's school has been pretty cooperative and helpful by sending us a tutor and also allowing us to attend school together, considering that is the only way he will go. I am unable to do this daily considering I have a younger son that requires my attention as well or at least someone to care for him while I am gone.**

**Unfortunately, PANDAS is all new territory for the school, and our pediatrician's office whom don't seem to know much about it.**

**I pray for a cure as well as more research to allow us to know more about PANDAS and educate our schools, doctors and people in the community that deal and work with children. We have not found anything at this time that has given him any relief from the symptoms of PANDAS. It's a lonely, lonely, place to be.**

**My husband and I are planning to attend on Friday March 1st. Thank you.**

**Allison Slowikowski  
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Nancy Flaherty, PANDAS Parent

Hi. My daughter Kaitlin Flaherty is 13 y.o. and has been suffering from Pandas (and autism) for a very long time. Her doctors (Dr. Denis Bouboulis and Scott Smith, PA) believe she has had it for years, and now Dr. Bouboulis has discovered that she has also had Lyme and its coinfections for years. Her symptoms were ignored for years. The pediatrician just told us that it was all part of autism. All we ever heard was that their wiring is off. We didn't know that others had sought help for their Pandas and had gotten better. We are just about to start her on antibiotics again, and hoping to get IVIG coverage from our insurance BCBS, b/c the antibiotics don't do well with her colitis and it's difficult to manage.

Kaitlin has increasingly over the years presented with many different symptoms, including, extreme anxiety, to such degree that you have to sit with her on the couch (and that's it, she doesn't want to get off the couch), licking objects, biting her nails, picking her nose, CONSTANTLY moving her hands/fingers, she has an OCD ritual where she rubs her thumb and pointer finger together and then rubs above her upper lip below her nose. She also swipes DVD boxes on her upper lip to the point where she causes the skin to break open and bleed.

These symptoms prevent her from having any quality of life, including interfering with the ability to go to school and learn. During her last flare last summer, she slept for only 2 hours a night, and would run around the house taking everyone's blankets off their beds b/c she was so anxious and frightened of the dark. It had a devastating effect on the entire family, including her parents and her younger sister and brother.

I had to take time off from work to help Kaitlin many days because her symptoms were so bad that she just could not attend school. My other children begged me to get her help because they were tired from not having been able to sleep at night. We were all tired and stressed out. It was horrible. Thankfully, Scott Smith, PA, was able to help us get out of the crisis with antibiotics HOWEVER, she still has many of the symptoms and we want you the LEGISLATURE to know our story so that you can recognize Pandas as a true medical condition and offer insurance coverage so that Kaitlin and others like her (and their families) can get help.

It's bad enough having autism but to suffer from Pandas too is just living a terrible nightmare. Please help Kaitlin and others like her. They deserve to be well and free from these terrible symptoms.

One last thing to tell you is that when Kaitlin's symptoms flare so badly her anxiety is so great that she has to take her dog into the shower with her. That's how crazy these symptoms are. I wish the school could also recognize the legitimacy of Pandas b/c they just treat it as behavioral issues which is also not fair to the child. And, the school needs to stop treating the parents as if they are crazy themselves for trying to advocate on behalf of their child with Pandas.

Thank you for listening!

Sincerely,  
Nancy Flaherty

Our son was a wonderful baby. Everyone says that about their own child – but in our case it really was true. He was an excellent eater – almost too excellent, and once he had his reflux under control as a newborn – hardly ever made a fuss. He hit every developmental milestone right on target – if he hadn't blown by it early already. Our family and friends used to call him the “floor model” because he was the child you showed folks who were thinking of having one themselves so they could see how “easy” being a parent really was!

He was walking and self feeding solid foods by 7 months. We always said it was because he didn't want the 3 older boys in his day care class to show him up. By 9 months old – we called the 4 of them the “diaper mafia” because they roamed around the room like a pack of hooligans. When the older boys all moved into the 1 year old classroom within 3 weeks of each other when Bummy was only 10 months old – he spent most of his day banging on the door of his classroom yelling to his friends across the hall. At that point his teachers nicknamed him “Brod-zilla” because when he wasn't looking for his buddies – he was re-decorating the classroom out of boredom. When he finally moved up to their classroom – we discovered who the Don of the diaper mafia really was – my son!

By the time he was 12 months old he had a vocabulary of over 50 words – by 18 months old, he was speaking in full complete sentences: “Mommy, may I have a cookie?” instead of “Mommy cookie” like other children his age. Before he left the 18-24 month old room at day care, his teachers favorite game with him was to write names of people he knew on the white board and have him read them – he could identify the names of every kid in his class, and most of the adults he came into regular contact with. He was a regular whiz-kid. Then everything changed.

When my son was around 17 months old (April 2009), he had an impetigo infection on his left wrist. It was a pretty bad one, eventually swelling to the size of a ping pong ball before abscessing. It was about 3-4 weeks later that we started to see changes.

It started one day with him biting a child at day care, I still have the incident report because it was the first one that involved him doing something wrong. We had plenty of reports of him being bitten – it seemed he was a target for one or two cannibalistic kids in his class. Sometimes, a bite went unnoticed because he wouldn't even cry - we'd see the marks when we got home and got him undressed. But him biting someone else? This was very out of character for him. He was a very passive child, not even retaliating when others hurt or bit him. It was the first red flag, but we didn't see it that way yet.

At first we didn't think much of it, since he had been bitten so often prior to this, we assumed it was only a matter of time before he picked up the bad habit. That first week, however, he bit 4 different children, multiple times. This would normally be cause for dismissal from our center, but the director was very understanding because it was so out of character for him.

It was so sudden and out of the blue, we all made jokes that someone must have slipped him the memo while he was sleeping that it was time for his "terrible twos" and to step it up a notch. He was making the other kids look bad.

About this time, he was also waiting for a spot to open in the 18-24 month old room, so we attributed some of it to boredom. He was always months ahead of his peers developmentally, so keeping him occupied at times was challenging in the baby rooms.

We continued to see escalating behavior problems, lashing out, pushing, hitting, biting, out of character for our son, but still all age appropriate for a typical 19 month old. We hoped when he moved up it would be better.

At the time he was about to move up, we opted to change centers. Our daughter was moving up to the pre-K 3 room, so we opted to go to a center that was closer to the pre-K/elementary school they would eventually be going too. We thought it would be an easier transition for both children the younger they were when we made the move.

Our son's class would be smaller than at his current center, so we thought that would help them stimulate him at a more appropriate level if he was bored. It was at this time that the separation anxiety started.

He would get very upset when I left him, and when I would return 8-9 hours later, his face would be swollen from crying, and they would tell me that it didn't stop all day. I should note that up to this point – he had NEVER had separation anxiety of any kind. I cannot recall a single time where he would cry when left at day care or with a sitter. He was a very easy going kid.

We assumed it was from the transition to a new place, and figured it would improve with time. It did - to a point – eventually he was only crying up until afternoon nap (around 4 hours). Needless to say – we didn't last 8 weeks at that center.

When we moved back to our original center where his friends and teachers were familiar, things were instantly better and back to normal. There was no biting even because now he was with his friends again in the bigger kid room – or so we thought.

That lasted all of a week.

The lashing out started up again, with some biting, but mostly hitting and aggressive behavior towards other kids. It was at this point that the OCD became prevalent (although we didn't know that at the time.)

In the morning, he would eat breakfast at school, and he started to pitch these uncontrollable fits every day. We thought it was because he knew I was leaving right after breakfast was set up and it was a carry over from the anxiety of the other center.

By the time of our dx at 26 months - his breakfast/drop off OCD ritual took me over an hour to do (assuming I got everything right) and his breakfast had to include a banana, a bowl of cereal with milk, a cereal bar, a container of yogurt, a package of pop tarts and a glass of milk. No - he did not actually eat all of this, but it had to be arranged just so or it would send him off on a tirade that included throwing chairs and hurting kids, it was bad.

Heaven forbid if the cereal bar or pop tart were cracked or broken. My husband often said that if he ever heard on the news of violence at the pop tart factory not to suspect terrorism, it was probably just me after having to deal with one to many broken pop tarts.

If he saw me even touch any of his food he would refuse to eat ANYTHING that was in front of him, it all had to be thrown away and start over. The same would go if anything was broken or if any milk spilled. He insisted on pouring his own milk and opening all of his breakfast - and you can imagine, the motor skills of a 2 year old really didn't allow this to happen without something breaking or spilling almost daily. It was nerve racking.

Breakfast was anxiety riddled all the way around. He was throwing a fit, and his teachers and I (as well as any other adult in the room dropping off their child) were all tied up in knots silently saying prayers that the paper towel didn't get wrinkled or the milk didn't dribble.

Then it had to be followed by a "super hug" ritual as I left the room that included him opening the door for me - if someone else came in or tried to leave during this process - it would set it all back to the beginning. I would then have to go into the hallway and sit on the floor (which was always fun in a dress suit and heels) and he would run down the hallway and give me a big hug that would tackle me to the ground (again - fun in a dress suit - I'm sure many a dad got an eyeful during this ritual!). As time wore on - he would have to give me more and more "super hugs" before I was able to leave. In the meantime - no one was allowed to come through the door during this time.

At pick up time, he couldn't leave the building without stopping to dump a large bucket of trains and line them all up (except for one, one little blue car always had to stay in the bucket - same one, every day. Not sure why, I always felt a little sorry for that lonely blue train).

He did this in the large play area in the center of the building where everyone had to walk through. If another child, even one of his friends, approached him while he was doing this (or God forbid actually tried to touch or play with the trains!) All hell would break loose. I can't count the times I had to carry him out kicking and screaming while my 3 year old daughter had to hang on to the back of my shirt while trailing through the parking lot. It was a nightmare.

Most of his problems really started at school - at home things didn't start out bad. However, over time, things at home started getting more and more difficult. Starting at

mealtimes, he would pitch fits if things weren't right with his supper. We tried every discipline technique in the book - nothing was working.

He was unable to make simple choices (you know, the ones you're supposed to offer a 2 year old to help them feel like they have control and prevent the tantrums? "Do you want the blue cup or the red cup?") No matter what choice he made, it was wrong, he would freak out, and even if we gave him the other one, it would still be beyond repair.

By November 2009 we were living in a nightmare. We were walking on eggshells around him at all times, we wouldn't do anything that might even remotely mess with his routine or schedule (we hardly left the house at this point other than work or church). If he was set off and had a tantrum – there was no stopping it. He would scream, cry and rage until he ran out of steam and eventually fell asleep. It could take hours. Nothing could pull him out of it – believe me, we tried.

For Thanksgiving that year, we had a big family vacation to Mexico planned for my parents 40th wedding anniversary. My mother planned and paid for the whole trip – and we were dreading it. We almost cancelled entirely when my mom called several weeks before and said our flights changed and it didn't jive well with nap time. We were that terrified of our son.

I won't get into the details of the trip – partially because I've blocked them from my memory, but I'll say this:

First, thankfully we brought a babysitter who stayed in the room with them when they were sleeping so my husband and I could go out with everyone for drinks in the evening - otherwise I'm not sure everyone would have made it out alive.

Second - if you're ever trying to smuggle anything illegal through customs, bring a 2 year old having an uncontrollable fit with you. He didn't stop the full hour we were waiting in customs for our bags. He was triggered by not being able to walk the way he wanted from the plane to the customs area. By the time our turn with the agent came he practically just waved us through to get us out of there. I think I heard the faint sounds of spontaneous applause when we left the area!

Things got progressively worse at school as well. We had lots of meetings with the director and teachers trying to identify patterns and interventions. Nothing. Thinking back, how our day care didn't kick us out for his behavior problems was beyond me! But we are thankful that they didn't!!

Only a couple of weeks after our return from Mexico, my husband's entire extended family came to town for the holidays, with his parents staying for almost 2 months. Because of the constant visitors, our son's schedule was practically non-existent. We tried every trick we could to bribe him into good behavior while everyone was here. We failed miserably, but fortunately, since his schedule was so off all the time, everyone just assumed he was tired and cranky and said things like "poor thing".

Just after the holidays, we started to notice big bags under his eyes. He was sleeping upwards of 16-17 hours a day, 12 hours at night, and a 3-4 hour nap at school (longer on the weekends). At school they would let him sleep as long as he wanted and didn't wake him when they did the other kids – probably a survival strategy!

Regardless of how much or how soundly he was sleeping, he looked like he was living in a crack den - strung out eyes, always looking pale and drained. We thought that all the excitement of Thanksgiving in Mexcio followed by the chaos of visits over Christmas was too much for him. He probably just needed rest and to get back to normal.

A couple of weeks after Christmas, when we didn't notice an improvement and his behavior had continued to regress to the point we couldn't hide it anymore from our visiting in-laws, the turning point came.

On Monday, January 28, 2010 - I got a call from the day care center. My son was having an uncontrollable rage. He was in the office, they had to remove him from the classroom because none of the tricks we had been using to help would make it stop. I had to come get him, they were sending him home for the day.

The next day – I got the same phone call. He had already passed out on a cot by the time I got there. The director, who has a PhD in special ed, pulled me aside and told me she felt comfortable telling me in no uncertain terms that she thought there was something seriously wrong with my son. She was very kind and caring, but said that she's known him from the day he was born, and from what she witnessed in the past two days especially, there was no reflection of my son's personality at all – he was a different kid and we needed to have him checked out. Immediately.

To be honest - I was so thankful to hear her say that. My husband and I had thought for some time that something was off, but our family and friends had all convinced us it was just the terrible twos, boys were just harder, and that we needed more discipline. If this was the terrible twos, it was the terrible twos on steroids!!

The next morning at 8:30 AM, January 30, 2010 we were in our pediatrician's office. Our pediatrician was a blessing!!! He had actually kept notes in our sons file of all the emails, calls, questions I had asked regarding behavior tips for our son – every off-handed question or remark he had noted. So when we started telling him the issues, he already had some history.

He immediately called out the OCD, as well as ODD and ADHD. The OCD revelation was huge to us because it put his rituals and tantrums into a new perspective that we could at least understand better.

We also realized at this appointment – pointed out by the Doctor's staff, how our son had regressed verbally. At 15 months he was speaking in full, complete, grammatically correct sentences, and now he was speaking more like a “normal” 1 ½ - 2 year old, short incomplete phrases – or hardly at all.

He offered a referral to a pediatric psychiatrist, but acknowledged it would take us a while to get in and they would likely want to medicate him. Something that didn't sit well with my husband and I for a 2 year old.

He then offered us another theory, PANDAS. He noted that my first email to him about the sudden onset of biting was only a couple of weeks after he was treated for impetigo – which can be caused by strep (although his actual infection at the time was not cultured.) So the timeline would fit. Even though the throat culture he did that day was negative, he thought PANDAS was still a possibility because of the timeline, and the description we gave in that first email back in May about how quickly his personality changed.

Our doctor offered to put him on a 30 day trial of abx (azithromycin) to see if that did anything. His theory was if we saw an improvement, we had a clue that we might be dealing with PANDAS, if not, it would take us a couple of months to get in with the psych so we wouldn't be any worse off than we were.

I will be honest – we love our pediatrician, but at this point in the game – I had absolutely thought he'd lost his mind. As we left his office that day I remember turning to my husband and telling him that we needed to find a new pediatrician. If he thought that some penicillin was going to transform the Spawn of Satan back to the sweet boy we used to know – he's nuts.

But, we tried the antibiotics anyway, what could it hurt?

Within 7 days the physical aggression was gone, within 2 weeks the tantrums went from raging until he passed out to only about 1-1 ½ hours. Still off the charts for most families, but for us, it was AMAZING. We still had a long way to go – but for the first time in months – we had hope that things were going to be okay.

After a few months on abx, we started working with therapists to help break the OCD habits. Because he had started them at such a young age, the fear was that they had become learned behavior.

In May of that year, about a year after his initial onset– he started with his first tics. It was a twitch in his mouth – almost looked like he was having a stroke, the left side would droop. Over the next 6 months, the tics would also include a teeth chattering, teeth grinding, and other facial grimaces.

We continued on the azithromycin for several months. Every time our pediatrician tried to take him off, he would regress back to square one within a few days. Eventually, our pediatrician acknowledged that while he had treated a few PANDAS cases prior to ours, none had been as severe or complex as our sons. All of his other patients completely recovered after a prolonged treatment with antibiotics. While we had become functional again, he still was not getting 100% better.

By July of that year our pediatrician referred us to Dr. Murphy, one of the PANDAS specialists (who also happens to be local for us). She confirmed our diagnosis and applauded our pediatrician for his approach thus far. Dr. Murphy told us our son was the youngest confirmed case she had ever seen – and even wrote up a case study on him.

Over the next 12-15 months, our son continued to improve on antibiotics alone, however, we also struggled with chronic strep infections. By the end of our 2<sup>nd</sup> year living with PANDAS, he was averaging close to 10 infections a year. He would contract strep even while on full strength antibiotics. We felt like we were on a roller coaster.

After his 8<sup>th</sup> or 9<sup>th</sup> strep infection of 2011, our pediatrician suggested it was time to pull his tonsils and adenoids. Dr. Murphy agreed, and we were off to the ENT. Our ENT agreed that he needed to have them pulled, and understanding a bit about PANDAS, even agreed that we should have preventative antibiotics during the surgery and for some time post-op. The ENT only suggested 7 days of antibiotics post-op, but Dr. Murphy and our pediatrician agreed that 4-6 weeks would be more appropriate.

We went into surgery Thanksgiving week 2011. Exactly two years from that hell trip to Mexico. He did well with the surgery, had a bit of nausea that day, but recovered quickly. The next 6 weeks were incredible. Immediately after the surgery ALL of his PANDAS symptoms disappeared. The tics – gone. The OCD – gone. He even began to eat so much now that the anxiety was gone surrounding his food that he gained 7 pounds in that 6 weeks. We were thrilled!!!

At Christmas time, we drove up to Buffalo, NY to spend time with my husband's family. It was on that trip that we noticed the hyperactivity creep back in. We dismissed it as a side-effect of being in a car for a 20 hour drive, staying in a tiny, overcrowded house for a week, being cooped up because of the cold weather, and all the excitement (and sugar) of Christmastime in general.

Unfortunately, it didn't get better. Upon our return, the 6 week antibiotic course antibiotics that he had been on lapsed. Within 3 days ALL of his PANDAS symptoms returned, and he tested positive for strep. Our reprieve was over – but it was wonderful while it lasted! It gave us new hope that our son could get better and that we were not dealing with a “new normal” filled with chaos.

In 2012, he had only 5 strep infections. A definite improvement over the last 3 years. Each time, the flare in PANDAS symptoms was less severe than what we had seen in the beginning. We have gotten so attuned to the tiniest change in his behavior, we've often been able to get him tested and treated for strep before things spiral too far out of control.

We have explored many avenues over our 3 year journey; have enlisted the help of another PANDAS specialist. We've run a myriad of tests – none of which have given us additional clues to our chronic strep problem. On paper – all of his test results are perfectly normal. The only clue we got was when blood work was run on the whole family, my husband turned out to be a suspected strep carrier. (Is that ground for divorce

in Florida?) He was treated, and cleared, and still my son got strep while on a strong combination of 2 different antibiotics. I'd like to say that my husband was still the culprit there – but he was on a 4 month business trip at the time. We have even treated our dogs for strep, replaced our AC system and all carpeted surfaces in our home to reduce possible contaminants and have had the house sanitized (including the air ducts and vents) on more than one occasion.

Just about the only thing we haven't tried to help is changing his diet. I know many parents describe improvements in their children's health and behavior from removing certain foods, adhering to a gluten-free diet, etc. But considering my little guy hardly eats at all, is in the 90<sup>th</sup> percentile for height and only 15<sup>th</sup> for weight, I can't bring myself to restrict him from eating whatever it is he wants when he is actually willing to eat.

Our son is now almost 5 ½, and we're still struggling, mostly with recurrent strep infections. The longest he has been able to be taken off antibiotics has been 5 weeks, back in December 2010. He continues to test positive for strep while on antibiotics. However, he has recovered back to about 80% when not plagued with a new infection.

He still struggles with eating, and hasn't gained a pound since January 2012. He still struggles with obsessive thoughts and ritualistic behavior. However, with the help of behavior therapy, we manage quite well. He attends pre-school in a special education setting, and is thriving. He'll be mainstreamed into Kindergarten next year, and is even being tested for the gifted program. He does gymnastics, and even likes to play with friends – when he's not in an active flare, then his best friend is the PlayStation.

With the help of the antibiotics and therapy, he has regained his verbal acuity, and therapy has given him many tools to express his anxiety when he's fixated on something. He's now able to verbalize things like "it's not right", or "I need 5" of whatever it is he's eating at that point (yes –all food and beverages are supposed to come in quantities of his age.) Where prior he would've just fallen to the ground in an aggression filled rage. Don't get me wrong – there's still anxiety driven tantrums, but now at least we have a clue as to why he's having them – even if that reason makes no logical sense outside of the OCD mind.

There have been lots of doctors, therapists, teachers and others that have helped us along on our journey thus far, including two well known PANDAS experts. But for me, our story has two very distinct heroes. If our day care director hadn't had the courage to be able to speak frankly to us about her fears for our child, I'm not sure how much longer we would've let others convince us things were "normal" before asking for help.

And our pediatrician – without him, our son would either have been diagnosed as Autistic and possibly lost to us for years, or been referred out for psychiatric treatment and given harmful psychiatric medications that are not approved for use in children, let alone toddlers. Our pediatrician has been our rock through this whole journey, a valuable resource and sounding board to talk through the treatment options presented by the experts. He has been willing to learn and has been open to any and all new information

we present to him. His approach to treating my son really has been “first, do no harm” and for that we couldn’t be more thankful.

He is headed for his first IVIG treatment in a little over a month. We are nervous to disrupt the balance we have achieved at the moment, but when he has an anxiety attack at mealtime, as he still does several times a week, we know it’s the right course of action. He continues to surprise us at how articulate he can be about his condition, even going so far as asking our pediatrician if he could continue on Rifampin because it made “Harvey go away for a while, but now he’s back again”. I remember how proud and profoundly sad the pediatrician and I were both at that moment – proud because he was taking an active role in managing his care, and sad that a 5 year old would be astute enough to know it.

We still are travelling along this arduous journey, and likely will for a long time. In the meantime, we continue to fight the good fight, pray for guidance, and give thanks that we have had wonderful people on our journey to help us.

Kind. Smart. Athletic. Articulate. Friendly. Lucky. Meet Matthew, my nine year old son who has PANDAS. He is lucky because unlike most children, he was diagnosed with PANDAS within a year. In 2008 Matthew presented with a sudden onset of tics.

Initially we weren't concerned because it was not affecting Matthew socially or academically. At that time Matthew's current tic was that he was constantly opening and closing his mouth. While visiting our family dentist, I asked him to check Matt's jaw and mouth to make sure everything was o.k. After examining him and telling me that he looked fine; I told him that Matthew had tics that came and went and seemed to change as well. He shared a story that his nephew had a tic disorder that was caused by strep. Thinking back, a few months prior, my youngest son had strep and Matthew had a rash on his body that was not diagnosed as strep right away. Matthew had previous strep infections that did not present as a sore throat, but rather as a stomachache and headache.

Keeping that conversation in the back of my mind, I started googling strep and tic disorders and read about Pediatric Autoimmune Disease Associated with Streptococcus which I never even heard about.

The next six months I watched closely as Matt's tics changed from nose scrunching to grimacing, from grimacing to raising his eyebrows, from raising his eyebrows to flapping his arms. Each time he had a strep infection, the tics got worse.

On March 31<sup>st</sup> Matthew had a very difficult time going to bed. He complained that his "brain hurt." A few hours later he screamed out for me. My son had a sheer look of terror in his eyes. He could not move and his large muscles were affected. His pupils were dilated - anxiety and fear swept over him. He did not want us to touch him or move him, in fear that he would get hurt. We could not talk to him because the sound of our voices was stressful to him. (increased sensory responses)

The next several weeks Mathew was not himself. He was very anxious at home. He experienced behavioral regression. He would hop around like a bunny and use "baby-talk." His teacher was puzzled because his subtraction skills that were once so easy were noticeably difficult. He appeared hyperactive and inattentive and lost his spark." We noticed a deterioration in fine motor skills and handwriting. Throughout these few weeks Matthew complained that "his brain wasn't working."

Looking up PANDAS for the second time, I was sure that Matt had PANDAS and that I needed to get to a PANDAS literate doctor to confirm the diagnosis. While my pediatrician was supportive and listened, he was not well well-versed in PANDAS and wanted more research. Fortunately, we were able to see Dr. B. Matthew immediately responded to the antibiotic treatment and is thriving!

**Today, I am here to share my story so I may help families and children that have not been as lucky as we were. We were lucky because our dentist planted a seed that allowed our family to become aware of PANDAS. Most families do not have that seed and are misdiagnosed for years at a high cost. It is urgent and important for more research and awareness of this disease (even for the medical community) and for the schools to recognize and support PANDAS children.**

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Thank You

## **Paula Voce, Grandmother of PANDAS kids**

My grandsons River and Reign have Pandas. River started having involuntary movements at age 8, the first movement was a simple giggle, over and over. Then other movements started to come with that and then he would stop a movement and another would take its place to the point of interfering with normal walking and talking. Then he woke up one morning in psychosis, talking to invisible beings, it went drastically downhill from there. He never sat down, walking constantly through the house talking and laughing to the voices. He eventually was not able to feed himself, stand up to go to the bathroom, take a bath, saw demons and skeletons coming out of the ceiling, became unable to communicate, refused his meds because the voice told him it would kill him and worse things. He lost 20 pounds. He was sent to Clarity House and was diagnosed with Pandas. WHEN SUBMITTED TO HIS PSYCHIATRIST AND NEURO WITH THIS INFORMATION IT WAS PUSHED ASIDE.

Finally about 6 months later I became so angry I told his psychiatrist I knew the answer was in his blood work, they were not taking the right test and I wanted a test for dopamine and serotonin levels. He snapped and said I bet it is strep. Sure enough the anti streptolysin confirmed his count was 680. In 2013 we are just now getting his count down to 114 after going through several doctors, some who refused to treat him. We have since found out his brother also has it and his involuntary movement was excessive blinking, his count was 540 and is now 399 which is unacceptable, but the infectious disease pediatric we are seeing is going by hospital standards that is that is okay. He also has been left with several involuntary movements he is on medication for. We have a heartbreaking three years trying to find physicians that have knowledge about Pandas, pretty much all of them do not. Dr Erika Gonzales, an immune specialist said they mentioned it in medical school but did not go over it as a medical tool. She would not help us because the immune system was okay but in the CT scan there was a sinus infection that had cleared up. Reign is asymptomatic and River has asthma, so we headed to Dr Hatch.

The moral of this story is the medical world needs to listen up and realize there are millions of children out there that are being misdiagnosed with OCD. OCD does not happen on its own, it happens because of the strep attacking the brain and when the count goes too high, psychosis. STOP telling us there is nothing wrong and refusing to acknowledge there is a problem here you are not addressing and refusing to acknowledge. STOP treating the parents like morons that do not know what they are talking about. THAT is your JOB, that is what you went to school for and proudly put the oath in your office. Help our children, mine have been tortured and disabled by this illness and thousands others are suffering right now. To the doctors that turned us away and refused to help or delve into finding an answer you should be stripped of your title, Dr Sidney Atkinson would be the first on that list. This is an ongoing problem that neurologists refuse to believe and are actually telling the patients is not true. We have lived it, we have seen the medications that helped and the problems left behind first hand. It is sad to believe you have to go to this extent to force physicians to learn about something that was already mentioned in medical school but dismissed even there.

Do your jobs, put through the grants and whatever is needed to help these children, doctors live up to your oaths and tackle the problem to find an answer. Without the Pandas Research network we would not have found the answer but we had no help from the medical world here in San Antonio. The printouts we took to every doctor's appointment was the helping tool.

Candi Rhodes, PANDAS Parent

Reagan was diagnosed ADD in first grade. She has always marched to the beat of her own drum. My daughter was what one would consider “normal” up until Kindergarten. During that year she started constantly pulling on her crotch area. I took her to her pediatrician, who had me change detergents, and put her on a pinworm medicine. Nothing worked. I continued to try all sorts of remedies, no underwear, soft underwear, underwear with panty liners, swim suit bottoms, etc...Finally, her pediatrician had me go see a pediatric gynecologist. Imagine being a Kindergartener and having to have an examine of your private areas. She ended up having surgery to hopefully help her not have the sensation of feeling wet. The idea was to remove any extra skin in the vaginal area that may be trapping urine when she went to the bathroom. Three weeks after the surgery we were in the exact same boat.

When Reagan was in the third grade, she started having severe panic attacks. She would go into major night terrors where she thought she would die. Nothing would calm her and we almost went to the ER on two different occasions. Her psychiatrist prescribed Ativan for whenever these episodes were severe. The Ativan did not help her at all. It was horrible. Finally after being on Zoloft for a few weeks the panic attacks subsided. Obviously, I did not want her on Zoloft because we already had her on Adderall for her ADD, but to have the panic attacks stop, I would have done anything.

Reagan has struggled in school because of her lack of focus, but my main concern was the tics she exhibited all day long. She would have to go to the restroom several times within an hour timeframe. Her pediatrician told me it had to be voiding dysfunction, so add this, to ADD, panic attacks, and now she needs a plan to help get her through a school day.

4th grade was a nightmare. Her tics were at an all time high. I took her out of school and home schooled her the entire year. This way, she could avoid the bullying.

I have been on a mission to find out what is wrong with my baby girl. I read an article, titled “An Unusual Presentation of Tourettes Syndrome” and thought this was probably my diagnosis. We tried treating her with different “tic” medicines still to no relief.

I have been stressing out about Reagan having to go to middle school next year because of the social impact of this disease’s manifestation.

This October I found an angel named Shreenath V. Doctor who specializes in PANDAS. He put Reagan on an antibiotic regimen and within three days ALL tics were gone.

Obviously this sickens me that I went 5 years without a diagnosis and all she needed were antibiotics. I pay around \$400 to visit Dr. Doctor because the pediatricians do not believe this is a "real" disorder. I know it is and will tell my story to anyone that will listen. Reagan has always been a very healthy child. I believe this is because her immune system was always "on" fighting strep. Her blood work came back that she has walking pneumonia and her strep levels are extremely high. I think a doctor should have recognized this.

Hopefully my story will help another mother/child so they will not have to go through the hell I've been through.

Thanks,

Candi Rhodes

## **Trapped**

**Malia Ott, PANDAS Parent**

The sudden onset of Ke'ala's symptoms started in December 2011 and advanced into January 2012 and beyond, disrupting our entire family and setting the course for a year of unbelievable turmoil. The first sign of abnormal behavior occurred the last week of December, when her 9 year old friend left the pool with a nauseous feeling, expressing his concern that he might "throw up". She ran to me with panic in her eyes and could not calm her fears that he was going to get sick. She was sobbing uncontrollably, with hands over her ears, curled in the fetal position on my lap for the ride home. This was not anything close to a reaction Ke'ala had exhibited until this point in her life. The episode passed but was followed by a similar, though slightly different, incident the next day with that same friend while at the movies with a half dozen people in the group. She had laser-focus on that friend and couldn't clear her mind of the thought that he was going to be sick (he was happily enjoying the movie with no signs of distress). That day passed, but Ke'ala's mood had changed almost overnight and she was unnecessarily wary of somebody, anybody, getting sick in her presence.

We employed the services of her existing clinical psychologist and sought the services of a psychiatrist as well. This is where our story became truly scary. At the advice of these professionals, we began a course of psychotropic medications on a "trial & error" basis ("trial & error" being the term THEY used to simplify to us how the mental health treatment protocol works). The first course of medication was Celexa daily supplemented with Ativan "as needed" for more severe panic episodes. After being on Celexa 2-3 days, Ke'ala had a panic attack surrounding a fear that her brother would be sick, not being able to calm herself with the coping skills being taught by her providers. We administered a dose of Ativan, as recommended, which sent Ke'ala into a suicidal state. She began saying that she would rather not be here, wanted to go to heaven (even hell if it meant not being HERE), began describing how she would do it (stab herself in the stomach was what she mentioned), began sobbing uncontrollably and had no signs of being able to come out of this state. We discontinued that pharmaceutical course and were advised to try Prozac and Abilify (to provide a short-term "bridge" to allow the Prozac to work).

Over the next few weeks, she became less and less able to be outside our home without experiencing panic attacks, leading to inability to stay in the classroom, inability to participate in extracurricular activities (swim, art, etc.), and she eventually became so anxious, that her bedroom was the only place she found solace. We had to physically carry her to the car (while she was kicking and screaming) to get her to leave the house. She would walk out, sprint for the backyard and refuse to get into the car. There were even incidents of her opening the door of a moving car, jumping out and running for the "safety" of the woods. In early February, with Ke'ala's inability to function outside the home, two options were presented: either school or the hospital. Ke'ala chose the hospital, unable to see herself being at school, surrounded by a bunch of children waiting to be sick. We brought her to the ER for an assessment and it was determined that admittance to the child psych unit was appropriate. Watching those elevator doors close with Ke'ala IN the unit and us leaving her was the single most heart-wrenching and frightening feeling I've ever experienced. Tears and cries for help from our daughter brought tears to my eyes, while I hugged my crying wife and tried to find any semblance of sanity in that moment. Little did I know that full sanity was not to be restored until a year later, when she was off ALL psych meds and back to her positive, thoughtful, cheery, energetic, engaging, generous, helpful self.

While at the in-patient psych unit, the first priority was to stabilize Ke'ala's mood, getting her stepped down from a suicidal state, then trying to find a diagnosis and transferring her to another facility to administer the care she needed. The medication protocol remained in effect and she was moved to a less-restrictive, yet still in-patient facility. At the next facility, Ke'ala put a bag over head early on, but eventually did show some improvement using the additional coping skills she was taught. The thought was to fine-tune the psych meds to keep her stable while continuing to work on her underlying anxiety disorder. The medication changed along the way, with Risperdal and Inderal used as well as the others. Upon discharge, Ke'ala seemed improved, but when asked to resume normal activities, she was unable to cope effectively. After three days, her CBT therapist had to recommend re-admission, as she presented to him with suicidal ideation, and he couldn't vouch for her safety. She was re-admitted to the same facility she left three days prior.

The second stay was longer than the first, and during this stay Ke'ala's medication was manipulated again to transition off Prozac (which didn't have any positive effect) and on to Zoloft. During this process, my wife was

informed about and researched an auto-immune disorder called PANDAS, the symptoms of which fit Ke'ala's very closely. After in-depth consultation with her pediatrician, the decision was made to test for Strep exposure and the resulting labs came back elevated, meaning that she was indeed exposed to Strep prior to her episodes in December. With this knowledge, Ke'ala was referred to an infectious disease expert, prescribed antibiotics, and within a week, her symptoms of anxiety lessened noticeably and within a month, she was markedly better.

Because she was unable to get back to her normal school, we applied for an IEP with our school district and underwent the process to get her into a specialized school equipped to handle children with an inability to manage in a traditional school setting. She is still attending that school, which is 25 minutes from home.

The amount of disruption to our family's lives during this past year has been unbelievable. The emotional roller coaster of multiple hospitalizations, the sleepless nights, the physically-draining drives to/from each hospital, the confusing diagnoses, the lack of any other treatment protocol than trial & error with psych meds - all made for quite a horrific year of turmoil. Thankfully, we had an insurance plan with an out-of-pocket maximum, or the financial aftermath would have been much, much worse.

Perhaps the most frustrating part of it all is the fact that much of the chaos could have been avoided if we were aware of PANDAS before this happened and knew the appropriate treatments available to treat our daughter. Because of my wife's initiative and determination to find some help, we were able to catch this disorder before things got to the point of requiring more invasive therapies like IVIG.

While we know that more awareness among the medical community is required to prevent this nightmare from happening unnecessarily to other children and families, we are so very thankful that Ke'ala is off ALL psych meds and we finally have our girl back!

April Schwarting, PANDAS Parent

Dear Legislators,

Our 11-year-old son, Andrew, who has been dependent on injected insulin since 27 months of age due to type 1 diabetes, has had 3 PANDAS episodes. As heart wrenching as it is to inject insulin into our son daily and prick his fingers to check blood sugars, dealing with the unknown causes and effects of PANDAS was the most frightening thing that has ever happened to us.

During these “episodes” Andrew transformed from being carefree and fun-loving to being extremely anxious and burdened by the need to repeat things or have things repeated over and over to him. During his first episode in 2007, Andrew suddenly (almost overnight) started asking the same questions and making the same comments repeatedly. (Up to 100 times daily.) These included telling me when he thought someone was fat, saying that he made a coughing noise (even when he didn’t), and worrying that he didn’t love relatives. These behaviors stopped 2 months later following a 10 day dose of Amoxicillin for an illness. By the time we met with Psychologist, Andrew’s problems had almost diminished.

Andrew’s “repeater thoughts” resurfaced in 2010. He started following all of his statements with, “Did you hear me, Mom?” even when I clearly answered him. He also had difficulty answering yes or no. He would say, “Yes, I mean I think, probably.” Suddenly, handwriting became torturous for Andrew. He began drawing his letters instead of writing them. I was fearful that we would have to take him out of school. I talked with a Psychologist about the possibility of PANDAS. She agreed that I should pursue this. Andrew’s family doctor started him on Amoxicillin. Within days, Andrews’s handwriting improved; however, it took a little longer for all of the symptoms to subside.

Andrew’s “repeater thoughts” resurfaced in 2011 and continued through the summer.

The psychologist was telling us that she was not convinced that Andrew was suffering from Obsessive Compulsive Disorder and that we should pursue the PANDAS diagnosis. We spoke to and visited pediatric neurologists, our diabetes endocrinologist, and an allergist in search of answers for this bizarre illness. It was extremely frustrating (and expensive) that no one seemed to give us clear answers.

The PANDAS network was a great source of information and some comfort to me during the most difficult time of my life. Please help fund more research into PANDAS and PANDAS awareness. I thank God each day that Andrew does not suffer from this horrible condition.

Sincerely,

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## Campbell's PANDAS Symptoms and Treatment

1. Early July 2012, all three kids had sore throats, fever, rash. Took Jordan in to the doctor. Coxsackie virus diagnosed.
2. July 10, 2012, road trip to Chicago. First noticed Campbell needing to use the restroom constantly. Campbell panicking about needing to pee. I begin to suspect a UTI.
3. July 12, 2012. Still on road trip. Campbell begins to confess every possible "sin" to me: "I think I used too much toilet paper", "I think I used too much toothpaste", "I spilled water on the floor and didn't get every drop up". I become concerned not only because of her need to confess minutiae, but because of her anxiety over it. She needs almost constant attention from me. She "burns" her hands with hot water while washing them. (I later realize that she is washing them so often that she has rubbed them raw until they bleed). We put Bag Balm on her hands, and I tell her not to wash them until they are better. I assume her anxiety is related to wanting to be "good" for Grandma, and hope it will resolve when we leave.
4. It doesn't resolve when we leave. End of July 2012. Campbell is now spending most of her waking hours checking everything with me. She still pees all the time. I started to think that I will spend my entire vacation in the bathroom. When we return home, I start her on D-Mannose for the suspected UTI.
5. Early August, 2012. Campbell has now washed her hands raw again. She continues to be concerned with every little thing. But now, she also comes to me, terrified that she has done something wrong – but she is not sure whether she did or not. At the grocery store, she suddenly says she has stolen something from the store. Not today, but sometime in the past. She's not sure. She is crying over it and pulling her hair out. She wants to confess to the store manager. But we haven't been to this grocery store in years. It takes me half an hour to talk her down. We are late for our eye appointment because of this. She is concerned that she is not a Christian and will go to hell. This makes no sense because she has been a believer most of her life, but she is suddenly obsessed by the fear of hell.

I contact our friend, Janet Prindle, who used to run the NW Center for Family Service office in Lakeville. She told me that it sounded like Campbell was experiencing an anxiety disorder. She gave me a referral to Susanna Schindelar, LCSW in Canaan. But we both agreed to take a wait and see approach, hoping this will pass.

6. End of August, 2012 – I take Campbell to MACONY Pediatrics for light colored stools. I mention to Dr. Chang that she has now rubbed her hands raw from washing them 4 or 5 times. Dr. Chang does a throat swap, suspecting PANDAS. It is negative. (The doctor did not send it out for a culture.) She advises Campbell to only rinse her hands with cold water, and not to use warm water or soap.
7. September 23, 2012 – Campbell is afraid to go to bed. She is convinced that she will kill herself in the night. I ask for specifics. She says she will take the kitchen knives and cut her own throat or stab her heart. She says she will drink bleach. She suggests taking her dad's and my thyroid medication. I discuss going to the hospital if she wants to kill herself. She says she doesn't want to, but she is afraid she will. She sleeps with me that night. Neither of us sleep much.
8. September 24, 2012 – her brother has had a sore throat for about three weeks, and Campbell is complaining of an ear ache. We get an appointment to see Mr. Reinhauer at MACONY Pediatrics. He says that Jordan has allergies, and is experiencing post nasal drip. He confirms Campbell has an ear ache in her right ear. He suggests wait and see approach. I tell him about her suicidal ideations. He asks if I am concerned she will go through with it, and I say no. But I do want us to get some sleep. I tell him I will call and make an appointment with Susanna Schindelar.
9. September 28, 2012 – First appointment with Susanna Schindelar, LCSW in Canaan, CT. That night we get word that my dearest cousin and his wife were killed in a car crash in Honduras. We were all quite close with them both. Campbell's fears ramp up. She refuses to sleep without me. I drug her with Benedryl to get some rest for both of us.
10. Campbell's ears get better, but her nose is running constantly. She begins burping, several times a minute sometimes. Seems to be involuntary. Comes and goes.
11. Over the weekend, I call Susanna Schindelar to discuss Campbell. She is now begging me to take her to the hospital as she is sure she will kill herself in the night.
12. October 1, 2012 – Second appointment with Susanna Schindelar. Return to MACONY Pediatrics and see Dr. Chang regarding Campbell's sinus infection. She prescribes 10 days of Amoxicillin. I discuss the suicidal ideations which have gotten much worse over the weekend. Campbell decides to tell the doctor what is really going on. Dr. Chang wants to order a full psych eval, but is unable to get us an appointment right away. Instead we see a Social Worker who works in their office. Campbell is

honest with her, and within 3 minutes we have a diagnosis of OCD. She tells me that OCD kids worry about suicide a lot. But that they do not actually commit it.

13. October 2, 2012 – Campbell begins a coughing tic. I am now convinced it is PANDAS with OCD/TS.
14. October 6, 2012 – Coughing in people's faces is a regular event. Brother and sister are getting annoyed. My three children who used to get along so well, are now at each others' throats. Burping continues, along with the coughing. Otherwise, she is able to function during the day. I cannot imagine what it would be like if we sent her to school. But we home school and I am grateful.

Nighttime is only slightly better. She wants constant reassurance that she will be okay. She is obsessed with poisons. She asks 4 or 5 times a night if her blankets, sheets, pillows or stuffed animals are poisonous. This has been going on for two weeks now. No amount of reassurance helps, so I have stopped doing it, fearing I am buying into the OCD. I tell her I love her and will see her in the morning. I do not let her sleep with me, as neither of us will get any sleep that way. I do give her Benedryl before bed to help her be sleepy. And we got books on tape at the library. I allow her to play them all night long if she wants, so that it will distract her.

15. October 7, 2012 – her nose is not getting better. The snot is still thick and yellow. Will call tomorrow for another appointment and push for Augmentin or Zithromax. Must get rid of this infection. Also will call Dr. Bouboulis (PANDAS Specialist) for an appointment. She is so tired. But at least she didn't get out of bed last night. She knows what is wrong with her. She is beginning to learn to tell the "PANDAS" to shut up. They won't shut up – but at least she doesn't have to listen to them.
16. October 8, 2012 – Called MACONY Pediatrics and got her Antibiotics (for her sinus infection) changed to Augmentin. Will take first dose tonight. Hoping for a miracle.

Third appointment with Susanna Schindelar. Seriously doubting this is helpful at all. I was very pointed with her about PANDAS, and she wasn't sure. She doesn't want to give a diagnosis. Doesn't believe in labels. We talked for most of the appointment. Campbell was able to share a little bit today about being so afraid. Still nothing helpful from these meetings at all.

17. October 9, 2012 – Called Dr. Bouboulis' office, and was told that they are taking appointments for new patients starting in April. That is over 6

months away!!

Spoke with Lily at NIH regarding the PANDAS IVIG study. She agrees that it sounds like Campbell definitely has PANDAS. But they need documented proof that Campbell either had or was exposed to strep. Seeing as Jordan is on week 5 of a nasty sore throat (his rapid strep test was negative a couple weeks ago, and the doctor said it was just post nasal drip from allergies), I am taking him in to MACONY today for more tests. Perhaps we will prove he has strep, and that would be enough to get Campbell into the NIH study.

If not, Lily at NIH said that she would work to get Campbell in to see Dr. James Leckman at the Yale Child Study Center. There's a wait to see him, too, but she said that if Cam doesn't qualify for the study, she'll get Campbell moved to the front of the list.

Or, perhaps one of the pediatricians at MACONY would be willing to treat Campbell with a consultation with either Dr. Leckman or Dr. K in Chicago?

18. October 10 -- I filled out a form on Dr. T's website. He's a PANDAS doc in NJ, with supposedly no waiting list. I hope that's true.

Campbell seems a little better. She is still very afraid, but she is able to rein it in, where before she couldn't. She's smiling and joking more. And I think she may be ticking less. But Jordan doesn't agree.

19. October 11, 2012 -- Hadn't heard from Dr. T, so I called them. Got an appointment for a week from tomorrow! However, they don't take insurance. It will be \$450 for the first appointment, and \$300 for the follow-ups. But I think it is important to cover our bases.

Meanwhile, more and more convinced not to continue "therapy" with Schindelar. She has taken phone calls during sessions. Last week she had to go downstairs and move her car, and then give her dog medicine in the middle of our appointment. When I mentioned PANDAS, she wanted to know if I wanted Campbell to go on SSRIs -- which are contraindicated in PANDAS. She doesn't want to label -- and I can appreciate that. But my kid is talking suicide every night. We are beyond putting stickers on a box, and making "safe" tents over our beds. I need real help for Campbell.

20. October 12, 2012 -- Called Susanna Schindelar to cancel Monday's appointment. Explained that we have an appointment to see a pediatric neurologist who specializes in PANDAS. He doesn't take our insurance, so we will have to pay out of pocket. We are cutting costs, therefore, and will be pausing our counseling sessions with her. She wanted to suggest

to we go through the house with Campbell and remove anything that she thinks she could use to hurt herself. I explained that this was not possible, as she is highly creative and intelligent, and can use almost anything to hurt herself. Also, although she has been scared of suicide for three weeks, she has yet to actually do anything to hurt herself. Mrs. Schindelar's recommendations, I suspect, are to cover herself in case Campbell should do something. They go against the treatment recommended in the "Freeing Your Child from OCD" book that I am reading. The book recommends not encouraging the OCD – not entering into the compulsions. Jon and I agree that hiding things from Campbell is not the way to go.

I also told her that the Augmentin seems to be helping. She agreed that if it could be treated medically, that would be the easier route. She asked to be kept in the loop, regarding PANDAS.

Tonight I began giving Campbell Ibuprofen. Have read on many PANDAS websites that it helps reduce the inflammation in the brain, and lessen the symptoms. I have not wanted to give it to her because it can be hemolytic. (Campbell is a "silent" carrier of Alpha Thalassemia.) But I do not know for sure that Ibuprofen is a problem.

21. October 13, 2012 – She slept through the night! Almost a normal day. Campbell did get very agitated in rehearsals whenever she got confused. But, on the whole, it was a decent day. Minimal trouble getting her to bed. She wanted to discuss things. I refused. She went to bed.
22. October 14, 2012 – Stopped giving ibuprofen because Campbell's gums were bleeding when she brushed her teeth, and then she had a gusher nosebleed. She seems to be doing better. Has started twirling her hair, absentmindedly.
23. October 16, 2012 – The ibuprofen was definitely helping. Two days without it, and she needs constant consolation even during the day. She asks permission for everything – wearing gloves or not. Changing clothes. Putting on a sweater. Getting a drink of water. She is so unsure of herself. This is not like her at all, but is the "new Campbell" I've been dealing with. Occasionally, like this morning, I see glimpses of the "old Campbell" – when she is so quick witted, and funny. She loves to laugh. But, mostly, she is anxious. I wish this would end.

I spoke with Dr. T's office, and I do need to order her records before we go. Will do that now.

24. October 17, 2012 – Campbell complains that her mouth tastes funny. Last night her dad read "Madeline" to the girls, and Madeline has her appendix

out. Not five minutes later, Campbell is complaining of pains in her side. She thinks she has appendicitis, and wants to be taken to the hospital. She is very concerned and asks repeatedly about it. We finally convince her that it's the PANDAS talking.

25. October 18, 2012 – Last night we got prayer for Campbell, and she seemed a little better. However, she was obsessing about something in a friend's basement that she thought might be poisonous. We were up late, but she went to bed without incident. This morning she had her last dose of Augmentin. Dr. T tomorrow for our first appointment.

Just realized that our probiotic may have had both gluten and Streptococcus in it! And, learned that most yogurt, milk, kefir, etc., have Strep in them, as well. Campbell is handling the news that she will now be dairy free pretty well. And I have located a gluten and strep free probiotic for her to take.

26. October 19, 2012 – Our appointment with Dr. T went very well. He went over her history with me, and asked questions about family autoimmune disease and OCD symptoms. He spoke with Campbell and did a brief exam. He took pictures of her eyes and mine in the same lighting, and showed me how Campbell's pupils were very dilated. She also has developed milking grip. Both are typical for PANDAS. He agreed that she has PANDAS and ordered bloodwork for the whole family, extensive for Campbell.

27. October 20, 2012 – Got the bloodwork done this morning. Campbell became very agitated during the blooddraw. I thought we might not be able to do it. This is not like her at all, as she has had blooddraws before with no problem. She fainted, twice, briefly after the blooddraw was over, and even seemed to seize a bit before coming to. We decided to have her stay home from her rehearsal today and rest.

We also filled the prescription Dr. T gave us for Zithromax. She is taking half the adult dose, thereby stretching it out to 12 days. By then we should get the results of the bloodwork back.

28. October 21, 2012 – Campbell seems much better today. She has energy, is laughing and smiling, and does not seem too overly anxious. She made it through an hour and a half dance rehearsal on skates, and only got distressed once – and then she was easily encouraged to continue on. I am so excited to see such a positive change in her.

She tells me that her pants were wet at rehearsal, and what she thought was sweat was really urine. I have ordered Poise pads for her – but she is quite upset about this.

29. October 22, 2012 -- Campbell was very anxious at bedtime tonight. Crying, and saying that I didn't understand and take her seriously that she wonders why life is even worth living. I tried to convince her that I am taking her seriously, and that the PANDAS are what is scaring her. That she's been saying for over a month she would kill herself, and she still hasn't. And that Dr. T said that PANDAS kids are afraid of suicide, but they don't actually do it. I finally agreed to give her an Ibuprofen. Will have to notice if she gets mouth sores or bloody nose this time – but maybe not from just one dose? I hope she will sleep tonight. Also, she's been taking melatonin at night. Otherwise, today was a good day.
30. October 25, 2012 – Giving Campbell melatonin and 1 Ibuprofen at dinner seems to be helping. Also, we had a good talk on the 23<sup>rd</sup> in the afternoon, when she was calm. I explained to her that every night, the PANDAS tell her that she's going to die that night. But here she still is. So the PANDAS are big, fat, liars. And she needs to tell them to shut up, and not listen to them. I also encouraged her that her dad and I love her; we believe her that she is super scared, and we are taking it very seriously. But we also know that she will be okay. And we all need sleep. She needs sleep to feel better. So she agreed to not listen to the PANDAS when they try to scare her. I also encouraged her to talk to her dad about her fears, because for the most part, it is on me. And it is just too much for one person to handle. This seems to have helped.

I also got her a chart today, and we are putting stickers on the chart for every night that she goes to bed without listening to the PANDAS. We are working on what the reward will be for filling in all the squares on the chart. She is excited about that.

31. October 27, 2012 – Tonight and last night the fears are ramping up again. She complains of headache around dinner time. Still giving her ibuprofen and melatonin with dinner. She comes to me at bed time, terrified. She is unable to tell a reasonable concern (like the coming hurricane) from a ridiculous one (“I am afraid some grass got in my mouth today, and I will die”). Tonight, I insist that we include her father in our discussion. She begs me not to. She only wants to talk with me. I tell her that I need her dad to know about this, too. I invite Jon in, and she slowly tells both of us her fears. She would keep us up all night telling us how scared she is, but, after half an hour of reassurances that go nowhere, we insist she go to bed, for her own well being. She still comes back out, five minutes later, to clarify with me. It could be a long night.
32. October 29, 2012 -- Much better night last night. She made a valiant effort to ignore the PANDAS. So proud of her.

This morning is much worse. Perhaps it is the barometric pressure from

Hurricane Sandy. I gave her an ibuprofen. She is exhibiting confessional OCD (telling me every little thing she does wrong, or almost does wrong) and high anxiety (worrying/panicking about things that are not important). Also, she was washing her hands repeatedly this morning.

33. October 30, 2012 – Even with Hurricane Sandy roaring, Campbell chose to go to sleep well last night. Unfortunately, her need for constant reassurance was still there in the morning. She is now policing everyone for anything they do wrong and tattling.

Tonight she did not want to go to bed. She is worried that she is getting worse. She is convinced she will get up in the night and take her father's pain pills (they were prescribed just today for his back pain). She is convinced that we do not understand. She says she doesn't just feel this way, it IS this way. I tell her that I am sure that she will be alright. And that her father and I, with God's help, and Dr. T will fight these PANDAS and win. She says she doesn't think God is helping. She is convinced that she will never be happy again. She is also worried about her father's back. She needs everyone to be well and happy.

She is also exhibiting signs of picky eating. She examines her food for any sign of contamination. Tonight at dinner she announced that her chicken was "too red". We looked and told her it was fine. She picked it apart, and ate very little. Afterwards, she was still hungry. I told her she could have some fruit, and cut up an apple for her. She wanted to know if the "white part" was moldy. I am worried that she is developing anorexia.

Dr. T's office was closed yesterday and today due to Hurricane Sandy. However, I was very blessed to reach a nurse yesterday who just happened to drop into the office to pick up a few things. She agreed to renew our Zithromax prescription, as it was due to run out today. It's not fixing everything, but I think it allows Campbell to function. I wouldn't want to see what life would be like without it right now. Test results will be delayed because of the hurricane. But, hopefully, soon.

34. November 9, 2012 - Campbell has been doing much better. The voices and obsessions are still there, but she is coping with them. She is being so brave. She tells me good night, and forces a smile. She is working hard to earn stickers for her chart by ignoring the PANDAS.

Campbell is eating well, too. Almost too much. She will often have second or third helpings, and doesn't seem to know when to stop eating. She still thinks that things taste strange or look dirty, but she knows that this too is just the PANDAS talking.

She complains of headaches still, and pointed out to me a bump on her

shin that causes her pain. She has other aches and pains throughout the day.

We have her taking ginger and curcumin pills, as well as olive leaf, bromelain and selenium.

Looking forward to our phone call appointment with Dr. T on Tuesday next to review the test results.

35. November 13, 2012 – Phone consult with Dr. T.

Campbell shows positive Coxsackie B Virus and Pneumococcal infection. This correlates with her initial episode in July after Coxsackie and the following flare with ear infection/sinus infection.

Picking up prescriptions tomorrow for Valtrex to try to get rid of the Coxsackie B Virus, and Omnicef to start in 5 days if no improvement. Continue on Zithromax until Omnicef starts.

Turns out, I, Paisley, am the strep carrier. Although Campbell shows no exposure to Strep. I am truly a carrier. I will start on Zithromax tomorrow. (I bet it is in my breast infection)

Tomorrow I will get copies of all test results, and call NIH re: IVIG study eligibility. She probably will not qualify.

36. November 16, 2012 – Campbell has now been on Valtrex for 2 days. On the one hand, we are seeing more of her sense of humor coming out. On the other hand, tonight she was a total wreck at bedtime. I had taken her off of the ibuprofen at dinner, but tonight I put her back on it again. She told me that she knew it was the PANDAS saying it, but that she was still scared that she would die in the night because of a blood vessel bursting. (We read about Attila the Hun dying in this way in school a couple days ago.) She could not be consoled. Finally, the ibuprofen kicked in and she was able to go to sleep.
37. November 18, 2012 – Campbell did better going to bed the last two nights. Will keep her on the ibuprofen for now. She is better on the Valtrex, but not enough. So tomorrow we will stop the Zithromax and switch to Omnicef, and see if that helps.
38. November 28, 2012 – Omnicef seems to really be helping. Campbell is about at 95%. She is still dealing with intrusive thoughts about death. But, between the Omnicef and the nightly dose of Ibuprofen, she is able to choose not to listen to the voices. She has one compulsion, which is to take her pills at the “exact right time”. She has the burping tic

occasionally. Otherwise, she is back to being Campbell.

I even noticed yesterday that her auditory processing seems much better. We were doing an assignment in "The Logic of English" listening to vowel sounds, and the other two kids were getting quite frustrated. But Campbell, to my astonishment, could hear and identify the sounds! We have a followup appointment with Dr. T. next Tuesday to talk about what is next.

39. November 29, 2012 – Started Campbell on a couple ounces of breastmilk today. Got it from a friend's daughter. Have quite a bit stored in the freezer. Hoping that it will work similar to camel's milk and reset the immune system. I ran it past Dr. T when we last spoke and he said he thought it couldn't hurt.
40. December 4, 2012 – Telephone conference with Dr. T. Told him that Campbell is doing much better. He suggested that we finish out the third refill of Omnicef (for a total of 30 days) and then switch to Azithromycin (Z-PAC) 250 mg twice a week as a prophylactic antibiotic. Will followup with bloodwork in January.
41. December 19, 2012 – Having finished up the Omnicef yesterday, today we started Azithromycin (see above). Will be taking one pill on Wednesday mornings and the next on Saturday nights.
42. December 20, 2012 – Campbell hit her head on the media center when she was dancing in the living room. Cut her forehead and has a big bump. Not feeling well. Having lots of PANDAS worries, apologizing a lot. Pupils seem dilated, but equal. Keeping an eye on her.
43. December 21, 2012 – Seeing many more signs of PANDAS coming back. She apologizes for every little thing. She is burping almost constantly. She gets another dose of Azithromycin tomorrow, but I am beginning to think that she needs to switch back to Omnicef. Wondering if we can do a prophylactic dose of that. I will call Dr. T after Christmas.

## Gabriella True, PANDAS Parent

I am a mother of an eight-year-old boy with Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS) and Autism. The neurologist told me that she could not help him as his symptoms were just due to his Autism. She did zero testing and would not discuss the diagnostic criteria. I had to find another doctor to help him. The doctor we see now does not take insurance. I can't afford too many of these appointments or I would be at risk of not being able to put food on the table. Too many families simply cannot afford to these doctors or the treatments.

When my son is having a PANS flare he is absolutely miserable; it turns your life upside down. One day he is a happy, autistic, non-verbal, low-functioning little boy, but nonetheless happy. But then suddenly, he is distraught, angry, unable to self-soothe, unable to sleep more than two hours at a time, barely enough strength to walk down stairs, wants to be picked up all the time, kicks, screams, bites, sobs, convinced he needs to eat constantly, and sometimes he has a tic. He usually can't make it through a full day of school. Since his PANS only presents a few times a year, his school has been unwilling to do a Functional Behavioral Analysis (FBA) and create a Behavior Plan (BIP) to help him learn how to work through these behaviors but instead send him home early. Thus he regresses in all his goals as he is unable to access needed academic support. I don't have a job, as I can't find a job that will allow me to take off for week or more at a time because I have to take care of my child during a flare.

A couple of organizations and parent groups have been a tremendous support. The parent groups are a needed support for those many hard times as well as place to discuss treatment plans, provide understanding, and ways to handle school issues. The fact that parents get most of their information on what PANS is and how to treat it from other parents and not doctors clearly shows how much the awareness among professionals is lacking. Too many parents learn about PANS through other parents and too many parents cannot find doctors who will diagnose and treat appropriately. Meanwhile their child has gotten worse; families are pushed to the limits of their patience and energy and then lose all hope.

In summary, we need the following:

- More doctors who are able to diagnose and treat PANS.
- Patients with Autism need doctors who will not dismiss PANS symptoms as merely "autistic-like" behaviors and therefore refuse to test, diagnose and treat.
- Doctors who understand the larger diagnosis of PANS and not dismiss the reality that pathogens other than Strep do trigger symptoms.
- More studies on how to treat PANS.
- Comprehensive insurance coverage.
- School districts must understand this condition and add appropriate supports.

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Grace Flanary, PANDAS Parent

My son used to love Gymnastics and dance class. He used to love to go to the zoo and see the animals. He loved going places with the rest of the family. One day in January 2011 he got a rash, while this rash wasn't unusual for him it, but was unusual is the rash wasn't gone 7 days later. We were told to bring him in after 7 days if it wasn't gone. We got the usual "it is a viral rash and nothing we can do". 2 days later he woke me up, upset that his thumb had a "blister" on it. Coincidentally we were off of school for a snow day. It was freezing cold and we had been playing out in the ice and snow the day before and I was worried about it being frost bite. So off we went back to the doctor and for the second time were unable to see our normal pediatrician. This time she took things a little more seriously and agreed that the rash ( which was still covering his body from head to toe) looked like Scarlet Fever. They did a rapid strep and a throat culture which both came back negative. I am still not convinced that it is not scarlet fever and for the next few weeks his hands and feet peeled starting with that blister. They peeled and then re peeled. He didn't like all the loose skin so after a bath he had to sit and peel all of it off. He had to keep lotion with him at school. He had dry spots on his face and shoulder. It was documented by the school and his dentist who was concerned over the peeling.

The day the irrational fear arrived we were going to dinner with a friend. They picked Flips patio and grill. The doors opened and he screamed and ran for the street. We were confused until we saw two life sized Polar bears greeting us. It took us 30 minutes and at least 3 tried to get in but he finally agreed and I carried him in through the bar area (still riddled with taxidermy) with his head buried in my arm. He sat through dinner without his glasses so he didn't have to see, and we got special permission to leave out the emergency exit. (Since he was going out that way anyway)

Things spiraled from there. His fear of heights got worse (he was already afraid of certain heights) he couldn't go in a glass elevator and no open steps. His handwriting deteriorated and his math skills plummeted.

His birthday came and he didn't want a party, he wanted to go play video games with his dad. There was not one person in his class or school he wanted to spend the day with. He was slipping away.

His behavior got worse and he started back talking and being mean to mom.

Something was wrong and we didn't know. We didn't know where our charming son went.

We were desperate and realized we had to do something. We couldn't take him anywhere due to the fears. It wasn't always taxidermy that scared him. Maybe a random statue that looked weird or was too big

On a field trip with school he had a severe panic attack about going into the Museum ( we still didn't know how bad it was) and had to be helped into a back door. We know now.

We tried to go to a restaurant. He saw the deer head first.

We realized we needed help and set up an appointment with the pediatrician who gave us a few phone numbers.

August we got the call that he could go to an extensive outpatient therapy at Cooks Children's hospital. He spent 7 days there getting worse every day. When we declined medication they were done, he was discharged. He got worse.

Summer was hard and he was bad, no one wanted him around. He was angry, mad and throwing tantrums. The tic (that he had since January) became nonstop and uncontrollable. He would thrust his chin out over and over again.

School started and we began wondering about the strep and Anxiety connection. PANDAS was mentioned and it fit, it all fit. Could the untreated Scarlet Fever have started ALL this? Could we have done more? What more could we have done, except trust our doctor.

The fight began. I called the pediatrician and he referred us to an infectious disease specialist. She was skeptical at first but even after the blood tests to check his blood titers were not high enough to show he had been infected with strep she agreed to treat with long term antibiotics. She called in 30 days of Cephalexin. 6 days later we were in the bleachers at a high school football game and we saw lightening in the distance and he calmly asked to get up and go home. We realized that we had a breakthrough. He was better and we believed that PANDAS was our answer. He told his sister that her hair looked beautiful. We hadn't heard anything nice from him in months.

After Halloween we decided to start Prozac.. We saw a little more improvement. The chin tic went away but the throat clearing one stayed. Later replaced by extreme eye blinking.

After 7 years of gymnastics he decided he was done. He didn't want to go anymore. His coach was "mean" or he was too scared to try. I was heartbroken.

Toward the end of the 90 days on Cephalexin we saw a plateau and realized the antibiotics were no longer working. Where do we go now? We trusted the one Doctor that would help us and we stopped them.

He is stable for now and although he has extreme OCD and asks the same things over and over again, he is still afraid to go some places with us. His school work is declining but he is generally "better".

Our biggest hope is to find more doctors willing to help us. A doctor willing to look into and study PANDAS.

How long will our son be sick? How many birthdays will he spend alone? When will he learn to socialize properly? When will we be able to take him to the aquarium? When will we be able to make plans that involve him and not finding a baby sitter for him? When will we be able to take a family vacation with him? What boy is scared of Lego Land? When will his sisters have their brother back?

When will the Doctors live up to the oath they take? "First do no harm"

In Nov of 2012 we got to put our son on a new insurance and we saw a doctor that treats PANDAS. We didn't even have to explain ourselves. He already knew, he knew the right things to ask. He knew the correct blood work to run. For the first time we were validated. We heard the words we already knew, but needed to hear it from a professional. He HAS PANDAS. Now we can take the steps needed to heal.

What did we find in the blood work? His thyroid was DOUBLE what it should be, His current and past levels for Mycoplasma were high, He is high for Current and past Coxsackie virus. We are on our way to getting our son back.

Currently we have stopped the Prozac. Did you know a psychiatrist can prescribe a mind altering drug without even checking to see if that is really what the patient needs? There is a simple test that can be done to check to see if it is even necessary.

## Jeannie Poirier, PANDAS Parent

To whom it may concern:

I have a 12 year old son with PANS. At age 8(June 2008) he had an upper respiratory infection/bronchitis and was prescribed antibiotics for 10 days. Two weeks later he had an ear infection and was prescribed another 10 days. About 6 weeks later, well after the infection cleared, he began with a few tics (nose scrunching, head jerking) then odd behaviors such as very impulsive, restless, anxiety, sensory issues, meltdowns and overly sensitive, could not sleep. I had no idea what was going on but this lasted a while and then he started eye rolling. To me it looked like he was having seizures so that's when I took him to his pediatrician. She had actually heard of Pandas took a strep test, and strep titer along with Lyme disease. Both negative and she said he did not have Pandas.

She sent us to a Neurologist which took 2 months to get the appt. By that time his symptoms had been slowing fading. The neurologist diagnosed him with transient tics and said just in case she was going to evaluate him for OCD. It took about 3 mos before I heard back from them and at that point my son was back to himself and I did not get him evaluated because nothing was wrong.

Fast forward summer 2011. My son seemed fine, no cold symptoms, but when he sneezed into a tissue it looked like an infection was brewing. Within a few days he had an ear infection and was treated with a 5 day course of Zithromax. After a few days I noticed he was rolling his neck again. He complained of a sore throat and brought him back to the Dr's. She said he had red bumps in his throat and diagnosed him with hand, foot and mouth disease and didn't prescribe anything. Then began the eye rolling again. Went through the same scenario with our Pediatrician again. Said it isn't Pandas because all tests were negative.

At this point I definitely knew these symptoms were infection related. So I made an appt at Boston Children's hospital to see a Neurologist. He said it was infection related but said that PANS/ PANDAS is controversial and gave us no treatment. Said he could possibly have OMS, Opsoclonis myoclonis syndrome. he said to call back if it happened again.

During this episode my son could not clear his sinuses, he was always stuffy, had bouts of diarrhea, very sensitive, the eye rolling tic took about 2 months to go away, but came back off on. He was very very pale, he was not doing very well academically. Next Dr an Allergist, and told him we thought he might have PANDAS. He said Pandas is controversial ended that conversation. He was given a nasal spray and Zyrtec. This just dried out his nose, we did not go back.

He was having a lot of anxiety, adhd symptoms. He hid under his desk at school because he was afraid, he also started banging his head at school and the school counselor said we needed to take him to a therapist. I took him and she talked with him for a few visits and stopped. She that he seemed fine and didn't need anymore visits.

I was done with this Pediatrician she was absolutely no help. The help I found was from the internet, searching and searching. The websites such as Pandas Resource Network were extremely helpful. I had no where to turn and everything on these websites made sense to me. It gave me hope. I found a great PANS Dr through this site( although we have to travel 2 1/2 hours to CT)and waited 3 months for our first appt. For the first time we weren't treated like WE were crazy. PANS wasn't controversial here. My son had several lab tests and was treated aggressively for the sinus infection that kept coming back for over a year.

We can not find a Pediatrician that believes PANS/Pandas exists in our area. We still get the look, and the usual comment that PANS is controversial from his current Dr. However, we just take our child to this Pediatrician for his annual physical because it's necessary and don't even mention PANS anymore. It's a darn shame when you can't discuss what's wrong with your child.

The elementary school my child attended thought I was crazy when I mentioned Pandas so I never mentioned it again. However at the middle school he attends now the school nurse heard of Pandas but had a lot of erroneous information. She has now been educated by us and our son is her first diagnosed PANS child at their school. We do not need an IEP or a 504 plan at this school because this is a Charter school and they personalize each child's educational needs. It's not a one size fits all school.

I really wish there was more research, more funding, more awareness and more Doctors that would at least accept that PANS/Pandas does exist. Let's get over this CONTROVERSIAL diagnosis and treatment. Let's get over this PANS/Pandas is "RARE" it's not rare it's rarely diagnosed properly.

Right now my son is doing very well since he's been treated. He's doing great academically, he's a model student, has friends enjoy's snowboarding, skiing, cross country and writing. What a difference treatment has made for him. I know he's not cured but we are in a much better place, finding support from our PANS Dr, forums and facebook sites. Families helping families.

Sincerely,

