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“Do infectious agents influence the development of autism, anxiety, or mood disorders? This remains a frontier area for NIMH research. The increasing evidence linking strep infection to OCD in children suggests that microbiomics may prove an important research area for understanding and treating mental disorders.” (Dr. Thomas Insel, Director of NIMH. August 23, 2010)

THANK YOU - NEW YORK STATE OT ASSOCIATION
For hosting this PANDAS / PITAND OT information Exchange!

Children with PANDAS/PITAND have sudden onset of problems in:
Handwriting
Sensory function
Separating from the parent
Emotional control
Urinary frequency/accidents
.... And others!
1. WHAT IS PANDAS/PITAND?

The National Institute of Mental Health (NIMH) has recently identified pediatric autoimmune neuropsychiatric disorder associated with streptococcal infection (PANDAS) and pediatric infection-triggered autoimmune neuropsychiatric disorder (PITAND) as a condition in a subset of children diagnosed with obsessive compulsive disorder (OCD) and/or tic disorders who experience abrupt exacerbations of these symptoms following an autoimmune infection. Researchers are currently discussing and debating the criteria for diagnosis as well as means of intervention for children with this condition, and even the name of the disorder may change in the near future. The director of the NIMH, Thomas Insel (2010) calls this disorder “a frontier area for NIMH research”.

2. SIGNS/SYMPOTMS

According to NIMH, the clinical diagnosis for PANDAS is the following criteria:

1. Presence of Obsessive-compulsive disorder and/or a tic disorder
2. Pediatric onset of symptoms (age 3 years to puberty)
3. Episodic course of symptom severity
4. Temporal association with group A Beta-hemolytic streptococcal infection (a positive throat culture for strep. or history of Scarlet Fever.)
5. Association with neurological abnormalities (motoric hyperactivity, or adventitious movements, such as choreiform movements)

The clinical diagnosis for PITAND is similar to PANDAS with the exception that temporal association can be linked to “any infection”.

In addition to the clinical diagnosis criteria, NIMH has also reported children exhibiting these behaviors that are associated with PANDAS/PITAND. AND often seen in OT!

<table>
<thead>
<tr>
<th>NIMH reports other behaviors in children that are associated with PANDAS/PITAND</th>
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<tr>
<td>Tics</td>
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<td>Obsessions</td>
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<td>Compulsions</td>
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<td>Choreiform Movement</td>
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<td>Major Depression</td>
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<td>Oppositional behaviors</td>
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<td>Hyperactivity (impulsivity, fidgetiness, or inability to focus)</td>
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<td>Joint pain and stiffness; general fatigue</td>
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</table>
WHAT CAUSES PANDAS/ PITAND??

1. A genetic pre-disposition to an abnormal immune response
2. The creation of an antibody that interferes with neuronal activity
3. A breach in the blood brain barrier, thought to be due to inflammation, that allows the antibody to reach neuronal tissue and interfere with neuronal functioning, including increased activation of calcium-calmodulin dependent protein kinase II (CaM Kinase II), a precursor to Dopamine. (Kirvan, et al., 2006; Moretti et al., 2008; PANDAS Resource Network, 2010; Swedo & Grant, 2005).

MEDICAL TREATMENTS...

There are no clear-cut standard medical treatments for PANDAS at this point in time. While it is generally accepted that antibiotics should be used to treat a known strep infection, additional treatments for PANDAS are controversial, and the NIMH cautions that extended treatments and immune-modulating treatments should be reserved for extreme cases. Treatments used for a child with PANDAS may include:

- Antibiotics - Short term to remove infection
- Prophylactic antibiotics - Long term to prevent infection
- Ibuprofen and other anti inflammmatories - to decrease inflammation
- Steroids - To halt autoimmune responses and decrease inflammation
- Plasmapheresis - To remove autoantibodies
- Intravenous Immunoglobulin Therapy (IVIG) - To provide healthy antibodies and “reset” the immune response.
### Motor Problems

- **Tics**
  - Assistive Technology (AT) if tics affect function - For example:
    - Weighted and/or built-up pens/pencils
    - Personal computer/word processor
    - Voice recognition systems

- **Weakness / Low Tone / Fatigue During Exacerbation**
  - Modify activities to accommodate for the deficit
  - Encourage activity to maintain strength and endurance
  - Use sensory tools to increase arousal (see below)

  Note: During remission - Strengthening activities

- **Joint Pain**
  - Energy conservation techniques
  - Warm baths – some families report good results with Epsom salts

  Note: If the child takes ibuprofen or other NSAID, plan activities after medication

### Cognition & Executive Function

#### Memory Impairment
- Assistive Technology
  - Lists (paper or dry erase boards), timers / calendars on electronic devices e.g.: cell phone, ipod, and computer, to keep child on schedule
  - Use school websites with online assignments and grades (if available)
- Cognitive retraining such as Brain Builders and neurofeedback

#### Attention to Task Issues
- Redirection

#### Preferences Seat

- **ive Technology**
  - Set timer on cellphone / ipod to give occasional vibration or sound to get child’s attention and return to task

### Language Skill Problems
- Give extra time for expression and reception
- Augmentative communication, cue cards or picture cards, if needed

### Math Skill Decline
- Extended time on tests
- Calculator for simple computation in higher grades

### Handwriting decline
- Built up pens / pencils
- Graph paper / vertical lines to improve spacing in writing and to line up numbers for math.
- Raised-line paper
- DANA / computer / Voice recognition software

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Continued...
### Emotional Or Psychological Problems

**Mood Changes (Sudden rages, Giddy, or Racing Thoughts)**
- Teach child strategies for control such as "safe" place to go to "get away"
- Calming techniques (deep breathing, weighted blanket, pet the dog)
- The Alert system / How does your engine run?

**Anxiety**
- Stress reduction techniques
  - Progressive Relaxation Exercises
  - Imagery
  - Yoga
  - Relaxation tapes

**Obsessive - Compulsive Behaviors**
- Support and reinforce Cognitive and Psychological interventions developed by trained psychologists or other professionals, including:
  - Cognitive-Behavioral Therapy or Exposure and Response Prevention Therapy
  - Positive Behavioral Support Plans
  - Redirection

**Sleep Problems**
- Sensory input
  - Deep pressure / weighted blanket
  - Electric blanket
  - Warm bath in Epsom Salt before bed
  - White noise, calming music, or calming audiobooks
  - Calming routines
  - Provide suggestions for bedtime/wake-time routines.

**Anorexia or Fear of Choking**
- Evaluate and treat any underlying sensory defensiveness (as noted above)
- Modify textures of food / offer moist food
- Work with family and psychology to re-establish routines as underlying infection is treated.

### Sensory & Perceptual Problems

**Somatosensory processing problems**
- Encourage activity to maintain strength and endurance
- Proprioception, deep pressure, and neutral warmth such as weighted vests / pressure vests/weighted blankets
- If sensory seeking - provide many opportunity for tactile input (vibration, different textures, different temperatures, finger paint, etc.)
- If Sensory defensive (avoid light touch)
- Decrease extraneous stimulation in room

**Visual & Auditory Perceptual Problems**
- Visual Perception exercises in remission
- TLP/Therapeutic Listening and similar programs

**Food Restriction Due To Oral Sensory Issues**
- and treat any underlying sensory defensiveness
- Oral desensitization such as deep pressure on hard palate with thumb
- Modify textures and flavors of foods to increase variety of diet
The “Doe” family (assumed name) consists of two parents, a 6-year-old daughter diagnosed with autism, and 2-year-old twin girls. The twins were diagnosed with PDD, and had a mild history of sensory issues including tactile defensiveness for both twins, and vestibular hyper-responsiveness for Twin A, with vestibular hypo-responsiveness for Twin B. In addition, both twins had language, and social skill delays and were receiving OT, ST, and ABA services.

In April, everyone in the family became ill suddenly with strep throat. After several visits to the emergency room, the entire family was placed on 7-10 day courses of antibiotics. The antibiotics seemed to improve the strep throat symptoms for most of the family members, but the twins continued to have symptoms, and their antibiotics were extended. During this time in April, the OT noted that both twins began having difficulty eating, with Twin A developing a strong food aversion and losing several pounds. Twin A also experienced severe separation anxiety when the mother walked down the hallway of their home and her sensory symptoms worsened considerably. She also experienced severe constipation and a sudden change in muscle tone throughout her body with her low muscle tone becoming even more hypotonic. She was unable to hold a crayon for more than just a few seconds.

Continued...
Gradually, over the next several weeks the OT noted a lessening of these symptoms in Twin A with a return to baseline. In August, the OT went on a 1-week vacation, and returned to find Twin A having severe separation anxiety again. The mother informed the OT that Twin A had been hospitalized for severe strep throat during the previous week. With documentation from the OT in hand, the Mother brought the sensory, motor, and emotional symptoms to the attention of the pediatrician, who closely watched changes in symptoms with strep throat diagnoses and identified Twin A as having PANDAS. The children were put on another course of antibiotics, were seen by a gastroenterologist, who treated Twin A for stomach problems. Both Twin A and Twin B were also seen by ENT, and had tonsillectomies. The twins continue to have an increase in mood lability, hypotonia and sensory problems, when they are getting sick. The mother is currently pursuing immunology consults for all 3 children to determine if there are immune deficiencies and answer the question: “why are my 3 children with autism always sick?!”. 

For additional cases see PANDAS STORIES FOR THE OT MIND beginning on page 11 of this document.
### PANDAS/PITAND ONLINE RESOURCES

<table>
<thead>
<tr>
<th>Additional Resources</th>
<th>Description</th>
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<tr>
<td><strong>Association for Comprehensive NeuroTherapy (ACN) Latitudes</strong></td>
<td>A nonprofit organization committed to exploring advanced and alternative nontoxic treatments for anxiety, autism, ADHD, depression, OCD, tics, Tourette, and learning disabilities. Provides a forum for individuals with PANDAS and their families.</td>
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<tr>
<td><strong>URL:</strong> <a href="http://latitudes.org">latitudes.org</a></td>
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<tr>
<td><strong>PANDAS Resource Network (PRN)</strong></td>
<td>A national non-profit organization dedicated to providing research, education, and awareness to the PANDAS. A wonderful resource for practitioners and parents to seek information on current Research. PRN also contains a registry of those families interested in research. This network is guided by a medical advisory board.</td>
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<tr>
<td><strong>URL:</strong> <a href="http://pandasresourcenetwork.org">pandasresourcenetwork.org</a></td>
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<tr>
<td><strong>PANDAS Network</strong></td>
<td>A wealth of information created by parents for families and physicians. Resources include research summaries for families, video-clips, and descriptions of several cases of PANDAS/PITAND.</td>
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<tr>
<td><strong>URL:</strong> <a href="http://pandasnetwork.org">pandasnetwork.org</a></td>
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<tr>
<td><strong>PANDAS Foundation</strong></td>
<td>Organization supporting research, advocacy and awareness for PANDAS. They also provide information for parents &amp; practitioners and have a connection to a Facebook page run by Beth Maloney, the parent of a child with PANDAS and author of the book Saving Sammy: Curing the Boy Who Caught OCD (2009).</td>
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<tr>
<td><strong>URL:</strong> <a href="http://pandasfoundation.org">pandasfoundation.org</a></td>
<td></td>
</tr>
<tr>
<td><strong>DR. MDK – Medical videos</strong></td>
<td>Videoclips by Dr. Susan Schulman describe one pediatrician’s approach to identifying and treating PANDAS/PITAND</td>
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PANDAS/PITAND is a recently-identified disorder, an autoimmune disorder resulting in the child’s own antibodies targeting the basal ganglia and interfering with function.

Children with PANDAS/PITAND frequently have problems with tics, OCD, sensory defensiveness, and handwriting deterioration.

This packet contains stories from the families themselves as they took time out of their hectic days to share information about their children and occupational therapy.

These stories show that OT interventions are needed, but the interventions provided are not always successful.

The occupational therapy community must come to understand the unique needs of these children and recognize that intervention must be tailored to the child AND to the phase of the disorder, using sensory tools, coping and environmental modification during exacerbation, while using remedial interventions and building skills during remission.

It is our hope that these stories will serve as a starting point for OTs to understand PANDAS/PITAND through the eyes of a parent.

Many Thanks go out to the families who entrusted their stories to us. Please read these stories with an open mind and an open heart. As occupational therapists, we have much to learn AND much to offer!

What are Parents saying about their children?

“Out of exacerbation he is a normally active, roughy-toughy boy but when in an episode that becomes extreme”

“He also had "rag doll" episodes where he would collapse to the ground, unable to move or sit up,”

“We found out that both kids are immune deficient in addition to having PANDAS”
I have a 7-year-old daughter and a 3-year-old son, both with PANDAS. My daughter was first recognized at 5 years of age, and she responded to antibiotics within 10 days and was fully remitted within 5 months. Her main symptoms were OCD with extreme emotional lability. She also presented with choreiform movements, tics, night waking issues, tremor, motor hyperactivity and sensory issues that included – In addition to those, things she had tactile defensiveness – she could only wear a couple of tops and a couple of bottoms. No socks and just 1 pair of sandals. Everything felt uncomfortable with seams or tags driving her insane. The clothes she did wear were soft and baggy. She didn’t want to bathe or have her hair brushed AT ALL (her hair got really bad for a few weeks). She was sensitive to loud noises, especially vacuums and toilets flushing.

These symptoms return when she gets sick. She has defiance and combative attitude, OCD, tics, nighttime separation anxiety, drawing regression, inability to learn, auditory hallucinations, visual depth perception changes, emotional lability and sensory issues that including clothing issues. She hated hoods in the car or wearing a coat in the car as they got ruffled up and uncomfortable.

One of the issues with bathing was getting dry. If there was ANY moisture left in her inner elbow crease or behind her knees, it troubled her. This sensation has been present to some degree during later episodes too.

She also started restricting food with one of her exacerbations. All her usual favorites didn’t “taste the same anymore” or she no longer liked the texture. Her diet became much more picky and junky, with food restricting being the symptom that took the longest to resolve. I am not sure if it was due to the sensory issues still being present or habit, I’m not sure.

My 3-year-old son has a history that is a little more difficult to document as he has only just turned 3, this week.

I believe, in hindsight, that his 1st episode was at the same time as his sister’s 1st recognized episode when he was 7 months old. He exhibited sudden and extreme separation anxiety.

Although, this is developmentally appropriate it was severe and overnight. He also became more “difficult” in general and his sleep, which was age appropriate got far worse with many more night wakings.
My son has sensory issues that become very bad during illness, and take 2-4 months to normalize after illness, including defiance, hyperactivity, aggression, getting stuck on something in an OCD kind of way, (though this is difficult to tell because of his age), stuttering/stammering, sleep disturbance and sensory issues.

His sensory issues include: Noise sensitivity (covering ears), sensitive to sock seams, possible vestibular issues such as he hates swings. He’ll get in but wants out as soon as they move. Will be throwing himself down the slide one day but as his PANDAS ramps will refuse to go down a few days later. He even went through a patch where he wouldn’t let his father pick him up because it was too high, wouldn’t sit on the kitchen counter etc. This is all in contrast to his otherwise rough and tumble nature. In fact, it’s his rough and tumble nature that can be the problem. Out of exacerbation he is a normally active, roughy-toughy boy but when in an episode that becomes extreme. It’s as if he needs really heavy contact and his aggression level goes up. When out of episode he will but very rarely hit or bite. This is an everyday…what feels like all day occurrence in an episode. He has to run into things and people.

It is because of the difficulty I have in managing some of this physicality/overload stuff that has led me seek an OT evaluation. I haven’t done this for our daughter as her issues have, so far, always remitted to an almost non-existent, supremely manageable point. This isn’t the case for our son.
PANDAS CASE 2: My Two Children have PANDAS with Different Behaviors

I have two children with PANDAS: A daughter and a son. Here is my synopsis:

**EARLY 2007**
In the winter months parents were talking about PANDAS on some message boards that I subscribe too. At the same time Katherine was having a hard time with focus and attention in Grade 1. She was 6. I had a hard time believing it was ADHD because it would come and go- very episodic.

She also had a terrible time holding a pencil and trouble writing that was also episodic in Grade 1. It occurred to me after a late round of strep in her classroom probably in April or May that her episodes of handwriting and the attention problems coincided with strep but she had never had strep throat.

**August 2007**
At the beginning of 2nd Grade we started to work with a private OT. Each week I got feedback, she assigned skills to work on at home and she gave me a progress assessment. At the beginning Katherine had decent handwriting so they spent time working on riding a bicycle and strengthening her core muscles. They made some progress. In the Winter months our OT noticed that the trunk work got more difficult. So did the handwriting. We thought that Katherine was goofing around. She also noticed that Katherine had started touching things in the room in a ritualistic way and stepping differently as if stepping over things and her handwriting deteriorated. Her behavior at home was terrible.

Her general behavior at school was good, she’s well liked at school but at home she was explosive. Attention was a problem especially when strep was around. She slumped down in her chair or held her knees to her chest, she could not tolerate Gym class or assemblies.
During the 2007-2008 school year I did take her to the pediatrician every time we received a strep notice from the school for her grade. We did quick and over night throat cultures. They were always negative. Two times in the late winter I was able to talk them in to blood draws for strep. All were negative and the pediatricians at that point challenged me, refused to do more blood draws without "having a talk" and started to treat me differently as if I were over reacting or had some personal problems.

2008-2009, 2009-2010
Katherine was placed in an integrated classroom where she did well with lots of support but "well" is a relative term. The behavior bar was lower and there was a Special-ED teacher in addition to the regular teacher who could explain everything away. Inside Katherine was in turmoil dealing with the PANDAS symptoms during the day and falling apart at home.

In the same time frame while all of that was going on with Katherine, Steven was being treated for viral problems that caused a lot of ups and downs. If there were ups and downs from strep they got lost in the big picture. He' has PDD diagnosis and is low tone, has mitochondrial deficiencies, and always had a hard time with writing. Really, he has always had so much going on that could be attributed to PDD that it was hard to see that it was likely to be PANDAS.

But overall he improved a lot in 2009 and because in general he was healthier it became much easier to see the pattern, to see that when she was sick with PANDAS he was sick with PANDAS and vice versa.

The main difference is that she is loud and oppositional and he withdraws and walks off seeming to not want to do anything, he seems to want to be left alone.

Except he does care, he is interested, he's disabled by strep and can't participate, can't write, can't draw. He's fatigued and depressed seeming. He needs big hugs, cannot walk long distances or play.

Similarly Katherine is interested in everything that's going on, but not functioning, not able to participate, angry because of it and ultimately disabled by strep. Like her brother she cannot write more than a few words, she reacts in anger at the process, she can not do math, she flips out in anger, frustration at math. But, she happens to be pretty good at math. Katherine also avoids sensory input during PANDAS, she does not tolerate touch or massage, she can't put on sneakers because she can't manage to fasten them or tolerate the feeling of them on her feet, and she can not sleep even with natural and prescription medication.

We introduced full time antibiotic treatment last winter, and sought the help of a PANDAS expert.

We found out that both kids are immune deficient in addition to having PANDAS. We are waiting to begin IVIG next month.
I have not had Max in formal OT sessions over the years but have utilized many "sensory diet" activities at home. Max has had PANDAS related exacerbations since he was about 8 or 9 years old. We have always seen mood changes and an increase in OCD/tic behaviors around the time of an illness but I have always attributed it to fatigue, being uncomfortable etc.

My son is definitely experiencing his most intense sensory issues now. I mentioned that he finds taking a shower, scrubbing his head, or toweling off very noxious. He also has hypersensitivity to brushing his teeth or cutting his nails. He finds sucking on a washcloth to be calming.

He has never been a sound sleeper. The use of a fan (white noise) is helpful. He also uses a heavy denim comforter when sleeping as he likes the weight of it. We have tried a brushing program with him in the past but it has not been very successful. We have also tried weighted items and resistive hard work but they have not been as effective as "cocooning" him. He finds water activities and swimming to be calming.

Max has found vestibular input to be calming and has always enjoyed swinging, bouncing, roller coasters, bike rides etc.

Many of Max's tics are facial in nature and he has a lot of jaw pain from his facial tics so activities regarding resistive chewing have not worked. He will do resistive sucking though and it seems helpful. One if his "competing responses" to his jaw tic is to push his tongue up on the roof of his mouth. It has helped in the past but is not working well right now.

Regarding school-related activities, I mentioned that Max tends to only write on the right side of the paper when he is having an exacerbation. I am currently trying to get more formal vision therapy for him but we are waiting for this current exacerbation to settle down so that he can tolerate the session better.

Max has always struggled with math but he has much more difficulty during exacerbations. I could never tell if he was just concentrating so hard on controlling his tics that he could not concentrate on math as well or if there were other factors. It is a significant change, however.
My son was originally diagnosed with acute rheumatic fever with Sydenham’s chorea (at age 11), since his initial symptoms (after a high fever) were migratory joint pain, muscle weakness, and difficulty walking.

About 6 weeks later, he started having "seizure-like episodes" where his limbs would twitch and jerk violently for 60-90 minutes. Over time, these choreic movements became more tic-like and he eventually developed vocal tics as well. He also had "rag doll" episodes where he would collapse to the ground, unable to move or sit up.

Soon after the chorea episodes hit, our son began developing severe sensory defensiveness. Light of any brightness caused him pain, and he would go into darkened rooms to escape it or wear sunglasses at all times. We had to put black drapes over his bedroom window (sealing them completely to block out all light) or he could not sleep. Smells bothered him tremendously, too; if my wife started cooking, he would sprint out of the room to avoid the cooking odors. Noise had a similar effect, and any loud noise triggered a major startle reaction. His sense of taste became acutely sensitive: foods he had always loved became "too spicy" or the flavor "too strong." Touch was an issue, too. He would only wear very specific pairs of jeans and tee shirts, had great difficulty finding socks he could wear (seams or tightness bothered him), had trouble at night because sheets were too heavy on him, etc.

We did try a local physical therapist after he was diagnosed with ARF/SC/PANDAS-related sensory integration disorder. She was great - sympathetic and supportive, said she had another patient with similar issues following "an infection" - but our son really didn't respond to the therapy, unfortunately. We discontinued it after several months.

All of these symptoms did resolve following multiple IVIG treatments and the “Saving Sammy” dose of augmentin XR.

PANDAS CASE 5: A Teenager with PANDAS and an OT Mom

I am an OT and have a 15 year old son with PANDAS. I can't believe it took so long to figure out what was going on with him. He has severe sensory issues when he has an exacerbation. He screams through showers and teeth brushing. He refuses to chew food that are difficult to chew (meat, crunchy items). He hates the feel of paper. He also has increased math problems and writes only on the right side of his paper. I have talked to a fellow OT who specializes in SI issues and have wanted her to be aware of all of the sensory issues that we have encountered as most of the kids that she has on her caseload are SI kids. I am so thankful that you are presenting on PANDAS.
We took my son to an OT at age 4 at the recommendation of his daycare teacher. He was having some fine motor issues, and sensory issues, and overall behavior issues that would come and go (this was prior to our PANDAS diagnosis). Our OT was great. Our son tested at the low range of several areas (vestibular, fine motor, and such). She worked with him for most of the fall. It was interesting hearing things from her perspective and through her lens. She was most surprised at the increase and resolve of some of his issues; he would be very difficult at some appointments and an angel at others. She even suggested we test him for allergies, as she didn't think sensory integration issues would cause the exacerbation/remission pattern.

After about 5 months with the OT, we finally discovered his PANDAS during a very bad strep infection. Once he was on antibiotics for 48 hours, he began asking to do his workbooks, color, paint, do mazes, dot to dot, you name it. This was the child that refused to even pick up a pencil from about age 2 1/2 to 4 it was amazing. I almost videotaped it. His OT had tried to teach him to use scissors for several months, even the specially made ones that are easier to use. The third day he was on antibiotics, he picked up his normal scissors, asked me how to use them, and then proceeded to cut everything I would let him, sitting on the floor in the kitchen for an HOUR, cutting away. His skills were still rough, but the interest and willingness blew me away.

I shared the diagnosis with his OT, and to the best of my understanding, told her that PANDAS impacts the basal ganglia, which is also the area that impacts sensory integration and function. She was fascinated, and shared my email with all her colleagues and the director of the OT institute. I asked for her help in jumping on this newfound interest in fine motor activities, and she provided us some great resources. They were all so open to learning about it, and I think were curious about whether it might also come into play for other patients none of them had ever heard of it.

We continued to go to the OT for several months, but have since stopped since we feel like we have a more complete understanding of his difficulties. I have seen the fine motor pattern continue. He came down with strep again several months later, and around that time he completely stopped doing any worksheets at preschool was not willing to do anything at all related to the fine motor.
PARENT STORIES

PANDAS CASE 7: Parent Shares Useful Tid-bits

My story is way too long, but let me just say, my son was way beyond Sammy, and we can write our own story. An important part of his ongoing therapy by homeschool teacher and can be filtered down to therapist is to keep a log/diary of drawings/and writings of child over a long period of time, catalog, DATE and KEEP them... so you can COMPARE and CONTRAST as child gets better... Ours was a very dramatic change from being neat, evenly spaced, good margins, very legible cursive, skipped every other line, free flowing thoughts to sudden tight fitting, uneven, off the page, hardly legible cursive with bad thoughts expressed for years, and then suddenly half through the PEX, we see the original way of writing reappearing and is present today. So, I would say handwriting is a pulse of progression to healing.

Oh another quickie...He was in riding therapy before getting so sick, and even while sick, I would take him to barn to ride our gentle former wild, white mustang mare who adored him. He would be so happy to brush her, be near her, hug her, rode bareback, she was careful to not go too fast, or hurt him... no biting or kicking ever..

She was a major factor to his healing. She was blind in one eye, was alpha of the herd, but was gentle with him.
My daughter began having hand tremors one and half years prior to her explosion in other PANDAS symptoms. It was such that she was evaluated by an OT (and neurology plus an MRI) but she wasn't really helped, only evaluated. When her major explosion occurred her hand tremors were so bad that she could not hold a pencil and had worn sores on her fingers due to pressing so hard to hold her pencil still. She also had entire upper body, including head, tremors with the pandas. Her math skills were GONE, all puzzle skills GONE (this is a child who was a whiz at puzzles previously—at age 3 was doing puzzles for 5-6 year olds independently).

You know that game perfection? She could play that, even with her tremors but when the explosion of PANDAS symptoms hit she couldn’t even fit one of those pieces in before the timer went off. But not only that she couldn’t even figure out that the pieces didn’t fit. She wouldn’t have been able to figure out that one of those baby ball shape toys didn’t fit in a giant cut out for it at that point (and she was 6).

The only ‘play’ she did was tie strings together and line up toys…that was IT. She scribbled like a toddler rather than a 1st or 2nd grader that she was. If the children were to make a design of a snowman, hers was completely unrecognizable.

She could run and speak but was terribly uncoordinated with a type of hunchback gate.

OCD was her major ‘sudden onset’ symptom (August 12, 2007—went on without breaks until IVIG November of 2008) and that was her confessing things she thought she did or thought she was going to do and was usually revolved around something evil. For example: She said thousands of times per day the following statements:

**“Mom, I just said a bad word”** (she didn’t---she would say this the second she opened her eyes in the morning and throughout the day)

**“Mom, my head just said that I am going to kill you”** there were times she would say this anywhere from 3 to 50 times EVERY 5 minute period of the day…. Estimate 100,000 times per day at worst.

**“Mom, I just smiled when you coughed”** (she didn’t)

**“Mom, I smiled when I looked at that”** (pointing to a cemetery we were driving past)

And so forth. We had a really horrible ordeal. She also had rage attacks but seemingly had nothing to do with the OCD/evil thoughts. And as per typical PANDAS rages, she bounced right out of them (after 4 hours) as quick as she bounced into one.

She ate strange things (napkins, rocks), thought she urinated on herself constantly, picked at her flesh until she had dozens of open sores. The usual stuff I guess. illnesses/tumors etc.

She was thought to be ‘mentally retarded’, ‘schizophrenic’ and autistic and it was brought up by more than one (I’m talking about BSN prepared nurses!) that she seemed satanically possessed! Can you believe? that?

I learned about PANDAS and she took antibiotics for 6 months prior to IVlg with little, if any, relief. She
was given several different antipsychotics and SSRIs, nothing helped. She was evaluated for many off the wall illnesses/tumors etc.

Basically she saw an OT twice, two years apart. One prior to any behavioral or mental health issues for the hand tremors (which I am sure play a part in the whole thing—a ‘soft sign’?) and then after her symptoms she saw an OT quite often in school until she went homebound. They helped in school with pencil expanders (is that the word?) and even help with eating at times because she could not get the fork to her mouth without the food falling off due to tremors. I am sure they did a lot more with her, but I was a freaking mess at the time so I don’t know what they did…she got tons of help from everyone even though nobody could really help.

The only thing that really helped her was IVIG. Today, she is doing very well (post IVIG). She is back in school and on the surface seems like a “normal” little girl.
These are a few examples of things my son has dealt with w/o OT intervention (he was 6-7 at the time, will be 8 next week).

Fire drills - the loud noise was very upsetting. Knowledge that a fire drill was upcoming would make him ruminate all day with anxiety. Thankfully, a classmate had Asperger's and used headphones during loud events. So my son felt less odd. He kept earplugs in his backpack (though he never used them, they gave him reassurance that he could get them if he got overwhelmed). The teachers put him in the front of the line so he was among the first out of the building to minimize his noise exposure. In my ideal, he would have been told when the drill would be (e.g. don't worry, the drill will be between 11-12 today) so he wouldn't stress all week (he knows that a drill is imminent in October during fire prevention week - spends all week worrying about it).

In 2nd grade, he left the art room to go to the bathroom and the fire alarm went off while he was there. He became confused about how to reunite with his class and there was much commotion in the hallway as classes got organized. He stood frozen near the bathroom until a teacher's aide from his class came to get him. For two weeks after, he was afraid to go to the bathroom - all day - for fear it would happen again. I spoke with the teacher and she spoke with the whole class, coming up with "what if" scenarios so they'd know what to do in different circumstances. Turns out several kids had similar fears.

General noise - my son hates loud kids. Becomes anxious when expected to just jump into an activity. So when possible, we get to school early (he will not ride the bus unless he has to due to noise and general anxiety of being with much older, boisterous kids). He waits with me in the car and watches the teachers and buses arrive. Then he's among the first into his classroom and he can acclimate to the room and noise levels as kids start to arrive. Instead of entering into things cold, he's already in the room and the kids are entering "his" turf, which is less threatening to him.

Vision and Hearing - at the worst PANDAS episode, my son failed his hearing test 3 times (only one specific frequency). He also failed his vision test. We had both checked when he was healthy and he had no issues.

Light - he will detect lights cycling or flickering when no one else does. When a light in the house dims because we turned on a hair dryer or a space heater in the bathroom, it distracts him from what he was doing and takes him a minute to regroup.

Handwriting - my son got help with his handwriting but it made him feel singled out and "dumb". My biggest fear about asking for OT is that I don't want to stigmatize him. He used paper with raised lines for awhile, but became embarrassed. What I hope can happen is that an OT can meet with him, evaluate him, then work with me so we can do things at home.

My biggest gripe about the whole experience is that I want so desperately to be a partner, an extension of what he learns at school, but often I feel like an intruder, that I'm supposed to hand my son over to "experts" and they'll take care of everything. They nod when I try to explain what's going on, but they don't get it. In ERP, a good therapist trains the parent to be a coach during the 100+ hours of the week that the therapist can't be with the patient. Why is this so hard for teachers to grasp?
Reading - this is a huge obstacle for us. My son gets in-school tutoring, but it's not directed at his disabilities specifically. As far as I can tell, it's generic practice and general reading strategies. In my son's case, his eyes seem to bounce around the page. He loses his place frequently and his fluency is interrupted because he's busy trying to find his place again. But in 2nd grade, they discouraged the kids from using their fingers or rulers, in an effort to increase their speed and reading groups of words at the same time. I wish teachers were more sensitive to how important it is to kids to not feel different. (tics and OCD already make him feel this way). So my son will not use tools that single him out. I need someone to assess him and identify which steps in the reading process my son is struggling with and give him compensation tools. It's not as simple as "practice practice practice". There are specific processing skills he's struggling with and I don't know what they are or how to help him.

Math - this has been my son's strength. But as we progress to multiplication, carrying numbers etc, he seems to be having problems holding all the information in his head. But he won't write things down and show his thought process. I believe he's having trouble getting information out of his head and onto the paper. There's something about the writing process that really bogs him down.

Writing (story composition)- ditto to above. He abhors writing. It is exhausting and takes so much energy to do the actually handwriting that he has little energy left to organize thoughts and put them on paper. He isn't ready for keyboarding - it takes so long to find the right letters on the keyboard that you can forget about getting a cohesive thought out of him. He does best when he can dictate a story. He has lots of good ideas, but struggles with the output process. Unfortunately, with 24 students, teachers often give a class a 30 minute quiet writing assignment and they touch base with all students maybe once or twice.

Guess who's staring at his paper most of that time, focused on how hard this is, instead of joyously sharing what's in his head? (he also got OCD and ADHD going on). One day, all he did was look around the room. The teacher got frustrated because she kept reminding him to focus and he couldn't. Turns out he kept having OCD tell him someone was staring at him. Every time he went to write a sentence, he had to look up and see if someone was watching him. He got 3 sentences written in 30 minutes.

I am so so frustrated with school. We moved to this town because of its excellent reputation. But the staff is just not prepared for kids with "rare" needs. They know how to deal with kids with traditional, constant challenges. But they are clueless when it comes to OCD, ADHD, or intermittent roller-coaster issues like PANDAS. They care, but they don't get it. I feel like I have a bright light who's been buried in an avalanche. I am anxious to free him and let his light shine. I feel like his self esteem depends on our being able to help him shine. He is a twice exceptional kid.

After losing most of 1st grade to horrible episodes (before finding a PANDAS doctor), my son's 1st grade teacher tutored him over the summer. At the end of the school year, we'd just started seeing a PANDAS doc and had done a prednisone taper, gotten on daily antibiotics (finally!) and did a T&A. The changes were so dramatic. The teacher told me in August "I can't believe this is the same kid who was in my class all year." She confided she felt my son might have Aspergers. But he was so outgoing when he was well that she couldn't get over it. He had kept all these ideas bottled up and they just gushed out that summer. I was finally taken off the neurotic mother list in her book!
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PANDAS/PITAND Resources:
NYSOTA children & Youth (for OTs)
www.nysota.org/sis_children_youth/#/

ACN Latitudes Forum:
http://www.latitudes.org/forums/index.php

PANDAS Resource Network
www.pandasresourcentwork.org

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www.pandasnetwork.org

PANDAS Foundation
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