TEN THINGS A NEWLY DIAGNOSED PANS/PANDAS PARENT NEEDS TO KNOW

Interrupting regular programming to talk about Chronic Lyme and PANS/PANDAS and Neuroimmune Diagnoses

My children and I are in NE treating Lyme, this is true, but the chronic condition my children are diagnosed with is actually PANS (Pediatric Acute-Onset Neuropsychiatric Syndrome, OR as it has morphed across the internet from the original moniker - Pediatric Autoimmune Neuropsychiatric Syndrome). This basically means my kids both have neurological and physical challenges associated with their illnesses.

I created this document for the parents who find their way to our Facebook Group. Our, meaning an organization I am currently working with. PRAI is a parent-led grassroots organization focused on educating the community on better recognition of PANS. We are reaching out and speaking with doctors, schools, and therapists in South Carolina (North Carolina and Virginia) as well as asking for an advisory council in each state. I also thought this might help anyone who finds my blog get up to speed on the acronyms and message board topics should they wish to explore the topic further. (Someone recently told me this was overwhelming. I agree, it probably is. Bookmark this page, print it off, make notes, rest assured you will come back to this information (not just here but across the web) time and time again and eventually you will be adding things to this list. As a new parent thrown into this - it is shock and awe, but you will quickly grasp your bearings, begin researching and before the clock strikes midnight, you will realize you have searched Pubmed backward and forward and are arguing treatment protocols like a pro! Read this once, keep it, pass it along, read it again, and when you know more, come back and update us, please. Crowdsourcing works for all kinds of things now, why not healing our children?)

TEN THINGS A NEWLY DIAGNOSED PANS PARENT NEEDS TO KNOW

1. **Understand the diagnosis and acronyms:** PANS stands for pediatric acute-onset neuropsychiatric syndrome, this acronym is also sometimes expanded to pediatric autoimmune neuropsychiatric syndrome. PANDAS (Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections) is a subset of PANS. There is also another (older) acronym – PITANDS, which stands for Pediatric Infection-Triggered Autoimmune Neuropsychiatric Disorders. “The NIMH Investigators discovered that the OCD, tics, and other symptoms usually occurred in the aftermath of a strong stimulant to the immune system, such as a viral infection or bacterial infection. The first cases were given the name PITANDS for Pediatric Infection-Triggered Autoimmune Neuropsychiatric Disorders. The first reported cases of PITANDS followed
infections with influenza, varicella (chickenpox), and streptococcal bacteria (strep throat and scarlet fever). (See Reference #3 for descriptions of the PITANDS cases.) Later cases were reported to occur in association with Lyme disease and mycoplasma infections (“walking pneumonia”). The NIH investigators chose to focus on OCD symptoms that occurred after streptococcal infections (the PANDAS subgroup) because of a connection between OCD and Sydenham chorea, the neurological form of rheumatic fever.” click the link to understand read in its entirety.

2. **Who is Susan Swedo, MD?** “Susan Swedo is a researcher in the field of pediatrics and neuropsychiatry, and since 1998 has been Chief of the Pediatrics & Developmental Neuroscience Branch at the US National Institute of Mental Health.” Wikipedia. Swedo wrote the first paper on PANDAS in 1998. “In the early 1990’s, investigators at the National Institute of Mental Health (Drs. Susan Swedo, Henrietta Leonard, and Judith Rapoport) were doing studies of childhood-onset OCD and observed that some of the children had an unusually abrupt onset of symptoms. Unlike typical cases of OCD, where symptoms begin gradually and may be hidden by the child for several weeks or months (because of their embarrassment over the irrational nature of the worries and behaviors), the children in the PANDAS subgroup reported a very sudden, dramatic symptom onset. The obsessive thoughts, compulsive behaviors, and motor or vocal tics appeared “overnight and out of the blue” and usually reached full-scale intensity within 24-48 hours.” NIMH

3. **Going to the doctor:** How do I know he won’t laugh out loud when I suggest PANDAS? Sadly, they probably will at least look at you sideways but always, your first stop is likely to be your pediatrician. This should always be where you go first anyway, however, it is probably better if you do not immediately suggest PANDAS; PANDAS is a subset of PANS and is strictly tied to a strep infection. If you ask about PANDAS, your doctor will possibly culture your child’s throat, see a negative rapid strep wand and move on. However, Strep can exist in multiple areas both in and on the body, it hides and is elusive; potentially, unless your child has a raging fever, a really sore throat with sore joints and body aches, your doctor will likely dismiss your thoughts of PANDAS. Sadly most physicians have now been taught that this is a rare disorder; however, it is estimated conservatively to affect more than 1/200 children. Parental complaints of misdiagnosis fill the internet rather than stories of their concerns being taken seriously. So we suggest (BEFORE going to your doctor’s office) that you print off a copy of the Diagnostic flowchart from PANDAS PPN and the guidelines for diagnosing PANS/PANDAS to take with you to the appointment. Be aware to firmly state to your doctor that anecdotally it is thought that a large percentage of parents who found themselves in this world did NOT experience a sudden onset with their children. Most had noticed odd behavior prior to the sudden onset of crippling OCD or TICS that their children experienced. It is also worth noting what OCD really entails because it is often not at all like they portray in the movies.

4. **The diagnostic guidelines** link above will allow you to read more on the many hidden OCD manifestations that you may have missed prior to realizing this debilitating
condition. Please also arm yourself with this information: Pace Foundation Guidelines

5. Q. If my pediatrician sends me away, how else do I get a diagnosis of PANS or PANDAS? A. Firstly leave the linked information above with your pediatrician. They may not have had time to read the latest research and standards of care for PANS patients, they should have but they genuinely may not have had time and it is worth discussing these flowcharts and standards of care with them. However if your pediatrician refuses to accept a possible PANS option or the care is limited at your family practice, you will be forced to move on. Technically these disorders are a clinical diagnosis but most doctors may want to run some (not all - perhaps request * first) of the following labs for infectious and vector-borne triggers.

a. ANTI-STREPTOLYSIN O Titers * (a measure of the blood plasma levels of antistreptolysin O antibodies used in tests for the diagnosis of a streptococcal infection or indicate a past exposure to streptococci.)

b. ANTI-DNASE B Titers * (blood test to look for antibodies to a substance produced by Group A Streptococcus. This is the bacteria that causes strep throat. When used together with the ASLO titer test, more than 90% of past streptococcal infections can be correctly identified.)

c. Streptozyme * (screening test for antibodies to the streptococcal antigens NADase, DNase, streptokinase, streptolysin O, and hyaluronidase. This test is most useful in evaluating suspected poststreptococcal disease following Streptococcus pyogenes infection, such as rheumatic fever.)

d. Mycoplasma pneumoniae IgG and IgM * (Two types of antibodies produced in response to an M. pneumoniae infection may be measured in the blood, IgM and IgG. IgM antibodies are the first to be produced by the body in response to infection. Levels of IgM rise for a short time period and then decline, often remaining detectable in the blood for several months. IgG antibody production follows IgM production, rising over time, and then stabilizing. Once a person has had a mycoplasma infection, they will typically have some measurable amount of mycoplasma IgG antibody in their blood for the rest of their life. In order to diagnose an active M. pneumoniae infection, a health practitioner may order both M. pneumoniae IgM and IgG antibody tests as acute samples and then collect another M. pneumoniae IgG test two to four weeks later as a convalescent sample. This combination of tests is ordered so that the change in the amount of IgG can be evaluated and because some people, especially infants and those with compromised immune systems, may not produce expected amounts of IgG or IgM) LabTestOnline
e. Lyme Western Blot and consider an IGenEX or Galaxy Lab test for coinfections of Lyme. Lyme disease is caused by a number of different strains and species of Borrelia bacteria, generally, Borrelia burgdorferi in the United States., while these two tests are typically more expensive than the standard Western Blot there is often more diagnostic success from these tests especially for - Babesia, Bartonella, Ehrlichia/Anaplasma.

f. IgG, IgA and IgM levels. *

g. IgG Subclasses, IgG1, IgG2, IgG3, IgG4

h. Ferritin * (iron levels: These tests can show how much iron has been used from your body’s stored iron. Tests to measure iron levels include: i. Serum iron - This test measures the amount of iron in your blood. The level of iron in your blood may be normal even if the total amount of iron in your body is low. For this reason, other iron tests also are
done. 

**ii:** Serum ferritin - Ferritin is a protein that helps store iron in your body. A measure of this protein helps your doctor find out how much of your body's stored iron has been used. 

**iii:** Transferrin level, or total iron-binding capacity. Transferrin is a protein that carries iron in your blood. Total iron-binding capacity measures how much of the transferrin in your blood isn't carrying iron. If you have iron-deficiency anemia, you'll have a high level of transferrin that has no iron.

**i.** Ceruloplasmin (Ceruloplasmin or caeruloplasmin) is a ferroxidase enzyme that in humans is encoded by the CP gene. Ceruloplasmin is the major copper-carrying protein in the blood, and in addition plays a role in iron metabolism.

**j.** Serum copper (Low serum copper, most often due to excess iron or zinc ingestion and infrequently due to dietary copper deficit, results in severe derangement in growth)

**k.** Vitamin D * (25-OH)

**l.** Pneumococcal antibody panel * (13, 14 or 23 serotypes)

**m.** CBC with differential and platelets *

**n.** Free T3, Free T4, TSH *

**o.** ANA with reflex *

**p.** Hemoglobin A1c

**q.** Coxsackie A titers/ Coxsackie B titers

**r.** EBV (Epstein Barr) Panel

**s.** HHV-6 titers

**t.** Parvovirus B-19 titers

**u.** B12, folate

**v.** SMA-20

**w.** Anti-thyroid antibodies *

**x.** Plasma amino acids because the symptoms of PANS/PANDAS/PITANDS are very similar, it is the trigger that differentiates the disorders. PANDAS is specifically triggered by strep, PITANDS by Infection, and PANS -: “The National Institute of Mental Health (NIMH) acknowledged that PANS, a treatable autoimmune condition, could be triggered by any number of infections (other than strep) and that patients could be diagnosed with the condition even if the infectious trigger(s) was unknown. In 2012, the NIMH released diagnostic guidelines for PANS. There is a growing number of publications on PANS, with the Journal of Child and Adolescent Psychopharmacology (JCAP) publishing a special edition on the syndrome in February 2015.” Moleculera Labs P.A.N.S. Most doctors currently use the PANS/PANDAS acronyms, but doctors are also beginning to refer to this as autoimmune encephalopathy/encephalitis (Encephalitis is often caused by an infection (bacterial, viral, parasitic) but can be due to autoimmune diseases. Encephalopathy is an altered mental status without a fever that can be due to many different causes including drug effects, lack of oxygen and toxins).

6. **How to find a reputable doctor to treat my child?** Join a Facebook Group. Other parents are often your best source of information but try to remember what worked for one probably worked for that one… all our children are different and all present differently. Allow a doctor the courtesy of diagnosing your child correctly (low iron, thyroid issues, and many other disorders can cause similar symptoms. Autoimmune Encephalitis can be life threatening which is a really good reason to fight for a correct diagnosis. Many parents manage symptoms at home by using homeopathy, essential oils,
along with pharmaceuticals, herbal protocols, and supplements to name a few. The message boards are awash with information, choose wisely and use those message boards to locate a doctor that most aligns with your preferred method of treatment (MAPS/homeopathic/integrative., etc). Most of the groups are closed and the admins will want to know if you suspect your child is heading to a PANS/PANDAS diagnosis before they accept you.

Some available groups (all can be searched from Facebook):
Homeopathy & Alternative Pandas Parents
PANDAS/PANS Institute (run by Rosario Trifiletti MD, PhD, LLC a leading expert in treating PANS/PANDAS and neuroimmune disorders in pediatric patients).
Parents of Children with PANDAS/PANS/LYME/TICK-BORNE
Recovering Kids| Biomedical Healing
Google your home state + PANDAS Parents Support Group to connect to local groups
PANDAS Autoimmune Encephalitis
Parents of Children with Autoimmune Unite
PAN(DA)S IVIG Insurance Triumphs

7. **Know the lingo**: An immunoglobulin test measures the level of certain immunoglobulins, or antibodies, in the blood. Antibodies are proteins made by the immune system to fight antigens, such as bacteria, viruses, and toxins. The body makes different immunoglobulins to combat different antigens. For example, the antibody for chickenpox isn't the same as the antibody for mononucleosis. Sometimes, the body may even mistakenly make antibodies against itself, treating healthy organs and tissues like foreign invaders. This is called an autoimmune disease. The five subclasses of antibodies are:

- **Immunoglobulin A (IgA)**, which is found in high concentrations in the mucous membranes, particularly those lining the respiratory passages and gastrointestinal tract, as well as in saliva and tears.

- **Immunoglobulin G (IgG)**, the most abundant type of antibody, is found in all body fluids and protects against bacterial and viral infections.

- **Immunoglobulin M (IgM)**, which is found mainly in the blood and lymph fluid, is the first antibody to be made by the body to fight a new infection.

- **Immunoglobulin E (IgE)**, which is associated mainly with allergic reactions (when the immune system overreacts to environmental antigens such as pollen or pet dander). It is found in the lungs, skin, and mucous membranes.

- **Immunoglobulin D (IgD)**, which exists in small amounts in the blood, is the least understood antibody. IgA, IgG, and IgM are often measured together. That way, they can give doctors important information about immune system functioning, especially relating to infection or autoimmune disease. [Kids Health](https://www.kidshealth.org)
**IVIG:** Intravenous Immunoglobulin Therapy. Immunoglobulin is part of your blood’s plasma. It has antibodies in it to fight germs or disease. When people donate blood, this part can be separated out. Then it can be given to you through a vein in your arm, or IV. If you get IVIg, it can help strengthen your immune system so you can fight infections and stay healthy. Liquid immunoglobulin is taken from the blood plasma of donors who are screened to make sure they are healthy. The plasma is tested for serious infections like hepatitis and AIDS. The plasma is purified before it’s used for IVIg therapy.

**Plasmapheresis:** Plasmapheresis or therapeutic apheresis is a “blood cleaning” procedure in which the child’s blood is removed through an intravenous catheter and processed by a plasmapheresis machine, which spins it to separate the formed elements (red blood cells, white blood cells and platelets) from the plasma (liquid portion of the blood which contains proteins, including antibodies and other immune components). The plasma is removed and replaced with equal volumes of albumin. The albumin is mixed with the child’s blood components and returned to his body through a second intravenous catheter. Because the blood volume to be processed is relatively large, and multiple procedures are needed, plasmapheresis often requires insertion of a central line (to ensure adequate venous access for both egress and ingress of the blood). In older children or those with superior antecubital veins, the procedure can be accomplished peripherally.

https://www.pandasppn.org/plasmapheresis/

**Rituximab:** Rituximab, sold under the brand name Rituxan among others, is a medication used to treat certain autoimmune diseases and (in much higher doses in combination with other drugs) types of cancer, it is a genetically engineered chimeric murine/human monoclonal IgG1 kappa antibody directed against the CD20 antigen. This is not a first line of defense and should be considered only with careful discussion with a knowledgeable provider.

**Low Dose Naltrexone:** (LDN) what is LDN “suggest that LDN may operate as a novel anti-inflammatory agent in the central nervous system, via action on microglial cells. These effects may be unique to low dosages of naltrexone and appear to be entirely independent of naltrexone’s better-known activity on opioid receptors. As a daily oral therapy, LDN is inexpensive and well-tolerated.”

**Mast Cell Disorder:** (cytokine storms). Many parents feel their children have this disorder in addition to or as a trigger for PANS or PANDAS. “Mast cell activation syndrome (MCAS), also commonly referred to as mast cell activation disorder (MCAD), is an immunological condition in which mast cells inappropriately and excessively release chemical mediators, resulting in a range of chronic symptoms, sometimes including anaphylaxis or near-anaphylaxis attacks.” Mast cell activation syndrome

**Suramin:** "... a small, randomized clinical trial conducted by Robert Naviaux, MD, PhD, professor of medicine, pediatrics and pathology, and colleagues at University of California San Diego School of Medicine have found that a single intravenous dose of suramin produced dramatic, but transient, improvement of core symptoms of autism spectrum disorder..." To help fund further research into Dr. Naviaux's cell danger
response research which may potentially benefit any autoimmune or neuroimmune disorder, you can donate directly Donate to Suramin Phase II Trial. 

8. **Is there a specific blood test to tell me if my child has PANS/PITANDS or PANDAS?** The Cunningham Panel™ aids in the diagnosis of Neuropsychiatric Disorders. This test is typically available through specialist providers of health care for children with suspected PANS; however, if you wish to order this test through your pediatrician they will need to contact Moleculera Labs and obtain a kit, the instructions are enclosed for the patient and the kit is shipped directly to your home. The patient locates a lab to draw the blood for testing and the lab typically ships the specimen by return to Moleculera. This may need to be completed at an outside testing lab such as Any Lab Test Now or a similar type location. To order the panel (you will need a physician): **How to order.** The purpose of the Cunningham Panel™ is to provide laboratory results to physicians as an aid in their diagnosis of Neuropsychiatric Disorders. This panel measures the level of circulating antibodies directed against antigens concentrated in the brain and measures the ability of these and other autoantibodies to increase the activity of an enzyme (CaMKII) that upregulates neurotransmitters in the brain. Cunningham Panel Neuropsychiatric Disorders tests: The panel consists of five tests. **Four of these tests** provide results that are expressed as a titer, or final dilution, at which an endpoint reaction was observed on an Enzyme-Linked Immunosorbent Assay (ELISA) format. These tests measure circulating levels of autoantibodies directed against specific neuronal antigens, including: Dopamine D1 receptor (DRD1), Dopamine D2L receptor (DRD2L), Lysoganglioside GM1, and Tubulin. Autoimmune antibodies that bind to these targets may interfere or potentially lead to a blocking or stimulation of the function of these antigens. This, in turn, may trigger movement and neuropsychiatric disorders, along with OCD and abnormal neurologic behavior. **The 5th test**, CaM Kinase II (CaMKII, Calcium-dependent Calmodulin Protein Kinase II) activation, produces a laboratory value (expressed as a numeric score) that reflects the percent above or below baseline CaMKII activity in a human neuronal cell line. **CaMKII is a key enzyme that is involved in the upregulation of many neurotransmitters such as dopamine.** CaMKII is also understood to increase the “plasticity” or sensitivity and responsiveness of neurologic receptors to neurotransmitters.

9. **Are there any dedicated treatment facilities?** Stanford was the first academic institution to start a multidisciplinary PANS service. They also hosted the first national PANS conference in the spring of 2013 where they worked to create clear diagnostic guidelines. Stanford along with the [The Pace Foundation](https://www.pacefoundation.org) are groundbreaking clinics. The Pace Foundation "as a strategic partner with the NIMH, the University of Arizona and Banner Healthcare, announced the grand opening of the 1st Center of Excellence (COE) in the world focused on Pediatric Autoimmune Encephalopathy (PAE) The Children's Postinfectious Autoimmune Encephalopathy (CPAE), on August 30, 2016. The Center treats patients and conducts world-class research on a wide spectrum of diseases (PANS, PANDAS and similar pediatric Autoimmune Encephalopathy disorders). Our goal is for the COE to open clinics throughout Arizona during 2017... The PACE Foundation is excited to be working with the National Institutes of Mental Health (NIMH) to facilitate cooperation
across a group of 13 Nationally Recognized Academic Research Centers across the United States. This effort will help standardize training, education, and treatment for patients suffering from Pediatric Autoimmune Encephalopathy (PAE) diseases like PANS, PANDAS and similar pediatric Autoimmune Encephalopathy disorders. “In reality, these two clinics will only serve you well if you are close to them so most parents have to rely on doctors who are out of network and often out of state. Pandas PPN has a search tool with doctors who will be able to help (Practitioner search) and again, other parents are often your best friend when picking a new doctor. DUKE University will treat some AE patients but some of my friends, have personally reported to me, they were turned away with a PANS/PANDAS diagnosis, ourselves included because we don't fit their criteria. Duke Neurology

It may be worth calling Pediatric Neurologists or Immunologists in your area to find out if they treat pediatric autoimmune disorders before making an appointment.

10. Ready to get more involved?
Reach out to your local PANS/PANDAS organization:
- MIDWEST PANDAS/PANS Parent Association
- New England PANS/PANDAS Association (some amazing graphics and information, especially for schools, are here).
- PANDAS/PANS Advocacy & Support IL based support
- PRAI KIDS Virginia, PRAI KIDS North Carolina, PRAI KIDS South Carolina (The group I am involved with).
- SouthEastern PANDAS/PANS Georgia based
Other Worldwide and US Support Group
Information can be found at www.pandasnetwork.org
other resources:
- www.pandasppn.org
- http://www.moleculeralabs.com/
- https://www.anylabtestnow.com/
- http://www.igenex.com/testing/how-to-order-test-kits/

10. Books:


PANDAS and PANS in School Settings: A Handbook for Educators by Patricia Rice Doran (Editor), Diana Pohlman (Foreword), Margo Thienemann (Contributor), Darlene Fewster (Contributor), Amy Mazur (Contributor), Janice Tona (Contributor), Kandace M. Hoppin (Contributor), & 1 more

For children: In A Pickle Over PANDAS Paperback – June 1, 2015 by Melanie S. Weiss (Author)
Scour the links provided in this document. These websites will give you access to published research, comorbid diagnoses, treatment options, doctor referrals

Bonus tip :D - Know that PANS/PANDAS treatments can be expensive, wine can be found in boxes. It may not be as elegant as glass bottles but it is certainly cheaper.