PANS
&
PANDAS

An Overview of the Current
Issues Facing Families

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DISCLAIMER

The context of this document is that it is provided for informational purpose only. You may not rely upon the facts and figures, prices or current assessments of treatment success rates as individual treatments will vary according to the persons unique biological make up. Price ranges are indicative only and may vary from provider to provider. Causation is at this time experiential and not based on peer reviewed studies.

While we have made every effort to ensure the validity of such information please be aware the topic is not without controversy from vested interests. It is a developing field of examination and not widely accepted in mainstream Western Medicine. It is called by other names and assessed differently in Western and Eastern Medicine.

Accordingly use your best judgement when referencing this information.

The opinions where they are expressed are those of author and not other members of the company.

THE FAMILY ISSUE

The first job of a parent is to protect their children, to keep them safe from all harm.

The second job is to raise their children, get the best for them to help them grow and thrive.

The third job is pass on skills and knowledge that can help the children survive on their own once the parents have passed.

These factors hold true no matter what the nuance of the culture or what designates a family. They hold true no matter who is vested or not in the process or how good they are at any part of the process.

Families encapsulate the individual and surround them with a barrier layer against the outside world. As societies and the human race has grown in size, distribution, variety and complexity. Struggles have appeared in the fabric of the human organization to address basic needs.

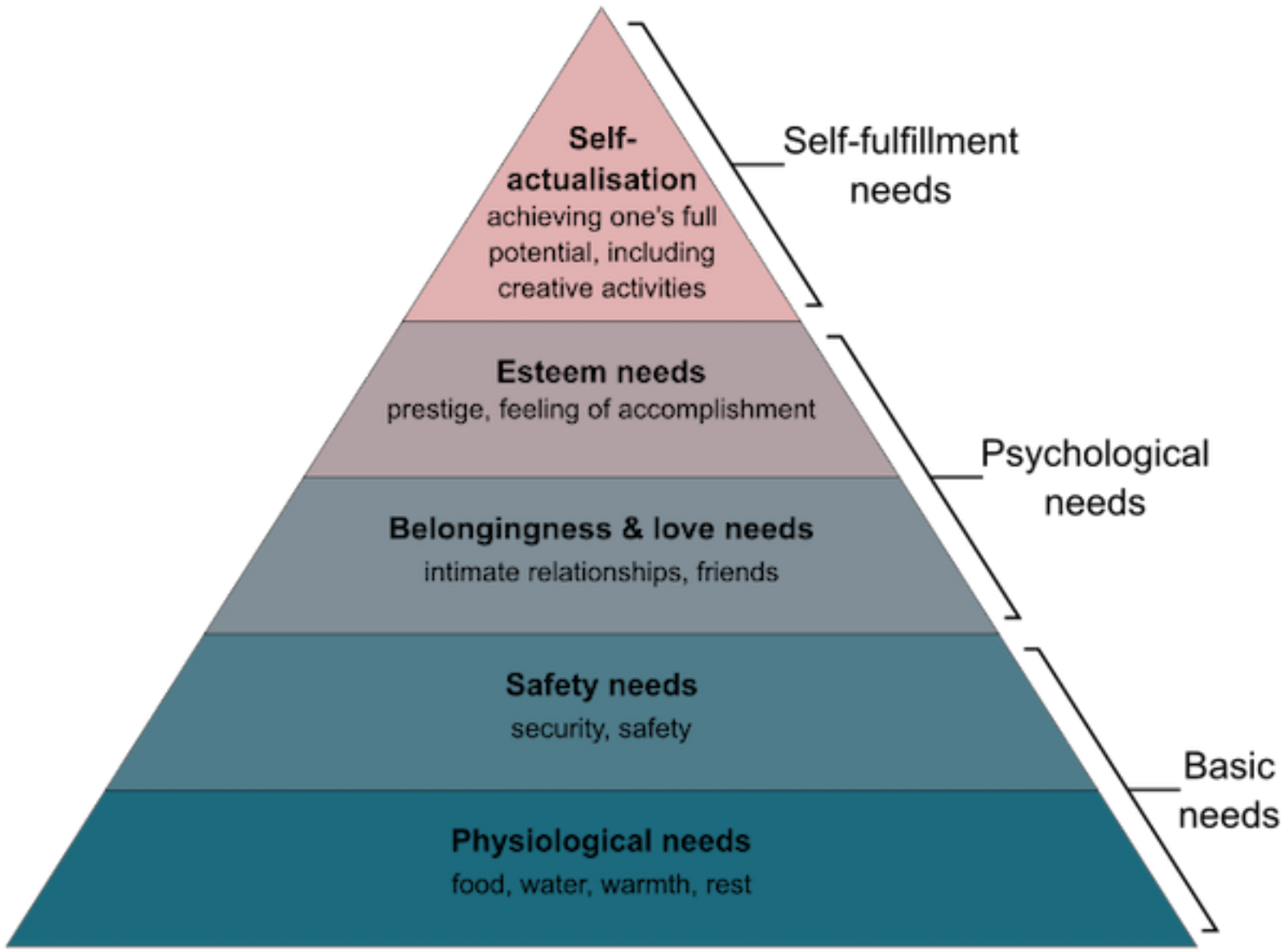
Basic Needs

A good place to start to define basic needs is to study the work of Abraham Maslow. April 1, 1908 – June 8, 1970). He was an American psychologist who was best known for creating **Maslow's hierarchy** of needs, a theory of psychological health predicated on fulfilling innate human needs in priority, culminating in self-actualization. Maslow was a psychology professor at Brandeis University, Brooklyn College, New School for Social Research, and Columbia University. He stressed the importance of focusing on the positive qualities in people, as opposed to treating them as a “bag of symptoms”. A Review of General Psychology survey, published in 2002, ranked Maslow as the tenth most cited psychologist of the 20 th century.

Maslow's hierarchy of needs is used to study how humans intrinsically partake in behavioral motivation. Maslow used the terms “physiological”, “safety”, “belonging and love”, “social needs” or “esteem”, and “self-actualization” to describe the pattern through which human motivations generally move. This means that in order for motivation to arise at the next stage, each stage must be satisfied within the individual themselves. Additionally, this hierarchy is a main base in knowing how effort and motivation are correlated when discussing human behavior. Each of these individual levels contains a certain amount of internal sensation that must be met in order for an individual to complete their hierarchy. The goal in Maslow's hierarchy is to attain the fifth level or stage: self-actualization.

Looking at Development as a Hierarchy

Though there are many that would criticize this body of work it is simple place to start to examine the complexities of existence.



Developmentally in our society we are experiencing a general trend to a smaller family unit with higher investment level in raising each offspring.

The Investment in Children

USDA recently issued Expenditures on Children by Families, 2015. This report is also known as "The Cost of Raising a Child." USDA has been tracking the cost of raising a child since 1960 and this analysis examines expenses by age of child, household income, budgetary component, and region of the country.

Based on the most recent data from the Consumer Expenditures Survey, in 2015, a family will spend approximately $12,980 annually per child in a middle-income ($59,200-$107,400), two-child, married-couple family. Middle-income, married-couple parents of a child born in 2015 may expect to spend $233,610 ($284,570 if projected inflation costs are

factored in*) for food, shelter, and other necessities to raise a child through age 17. This does not include the cost of a college education.

Where does the money go? For a middle-income family, housing accounts for the largest share at 29% of total child-rearing costs. Food is second at 18%, and child care/education (for those with the expense) is third at 16%. Expenses vary depending on the age of the child.

Expenses also increase as a child ages. Overall annual expenses averaged about $300 less for children from birth to 2 years old, and averaged $900 more for teenagers between 15-17 years of age. Teenagers have higher food costs as well as higher transportation costs as these are the years they start to drive so insurance is included or a maybe a second car is purchased for them.

Regional variation was also observed. Families in the urban Northeast spent the most on a child, followed by families in the urban West, urban South, and urban Midwest. Families in rural areas throughout the country spent the least on a child—child-rearing expenses were 27% lower in rural areas than the urban Northeast, primarily due to lower housing and child care/education expenses.

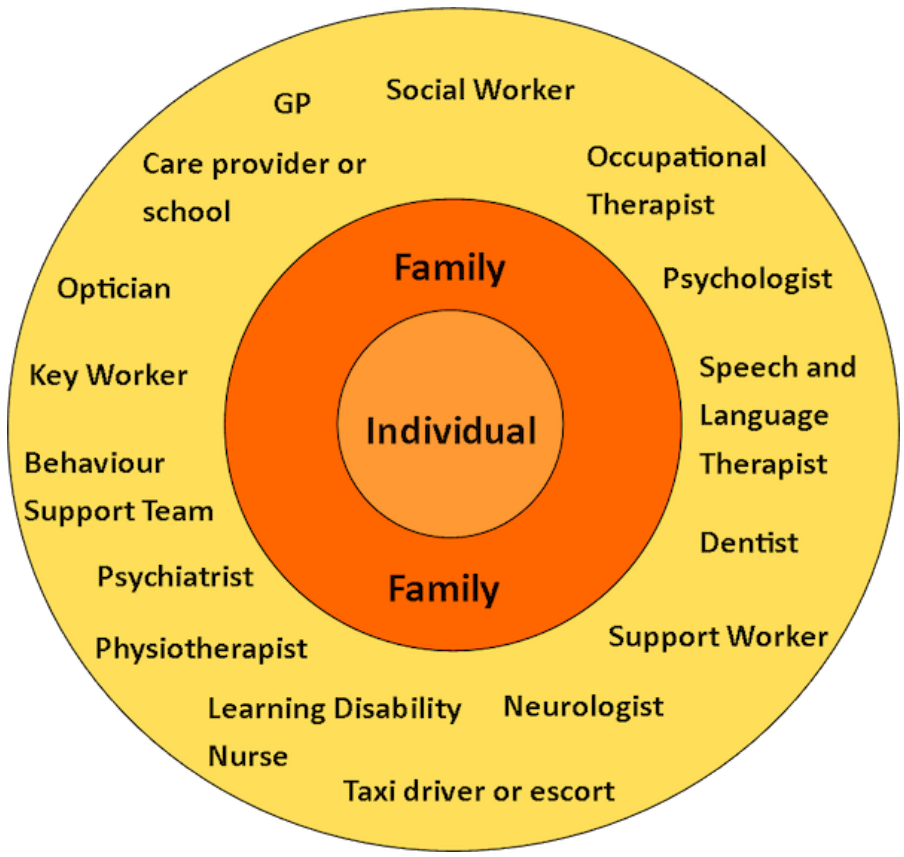
Child-rearing expenses are subject to economies of scale. That is, with each additional child, expenses on each declines. For married-couple families with one child, expenses averaged 27% more per child than expenses in a two-child family. For families with three or more children, per child expenses averaged 24% less on each child than on a child in a two-child family. This is sometimes referred to as the “cheaper by the dozen” effect. Each additional child costs less because children can share a bedroom; a family can buy food in larger, more economical quantities; clothing and toys can be handed down; and older children can often babysit younger ones.

The True Rate of Increase

It cost $25,299 to raise a child from birth to age 18 in 1960. This may be one of the many reasons Americans are having fewer children these days. Adjusted for inflation, the 1960 sum equals about $192,497. Therefore with simple maths $284,570 minus $192,497 equals $92, 073 or approximately a 48% increase in the underlying costs. There are many reasons for this and we shall examine a few.

The Family Circle

The increased investment in raising children has come with a large underlying cost. That is of complexity. It is no longer possible to simply raise a child. There are numerous hurdles that you have to face: The first one is the your child will be vaccinated just after birth with Hep B vaccine. You have to have a car seat that meets certain specifications before the hospital will let you take the child home. As the child grows so does the level of complexity. Currently, 16 vaccines – some requiring multiple doses at specific ages and times – are recommended from birth to 18 years old. There are numerous people holding positions of influence whose advice you are recommended to listen to:



Complexity does NOT Bring Safety

As any good engineer will tell you, the more moving parts you have in a system, the more likely the system is to fail.

- Complex systems are intrinsically hazardous, which drives over time the creation of defense mechanisms against those hazards. (Things can go wrong, and we build up mechanisms to try and prevent that from happening).

- Complex systems are heavily and successfully defended against failure, since the high consequences of failures lead to the build up of defenses against those failures over time.

- Because of this, a catastrophe requires multiple failures – single point failures are generally not sufficient to trigger catastrophe.The complexity of complex systems makes it impossible for them to run without multiple flaws being present.

- Because these are individually insufficient to cause failure, they are regarded as a minor factor during operations.

- Complex systems therefore run in degraded mode as their normal mode of operation!

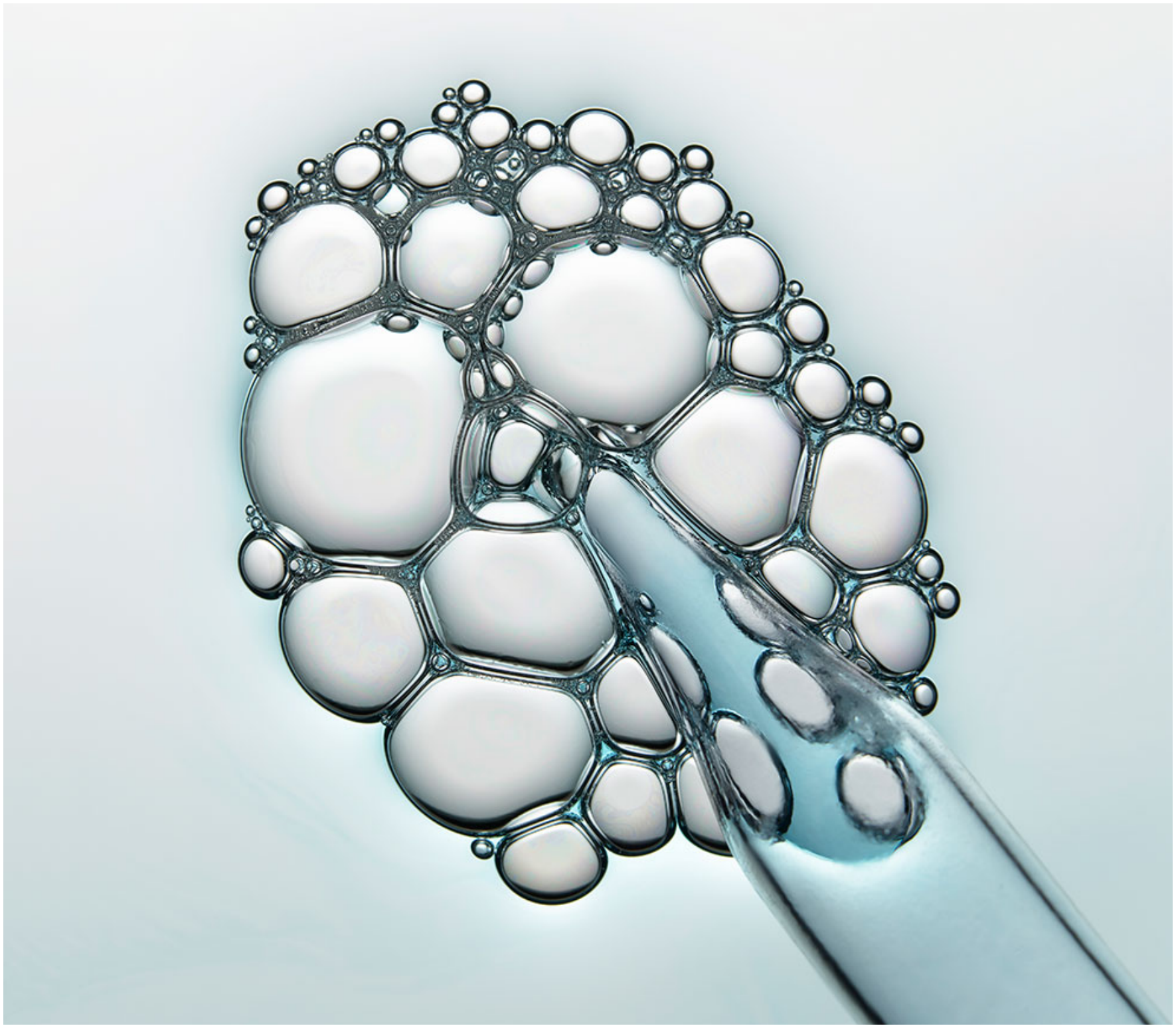
Summary

We find that the beginning maybe a simple issue such as a child's ear infection that get's treated with antibiotic (appropriately and completely or not) and combined with either vaccinations which have temporarily weakened or otherwise directed the immune system into other areas. Or an underlying genetic issue or a childhood trauma such as falls, breaks twists and sprains that never fully heal. Combined with a carb or sugar rich diet which depletes the gut microbiome. Stress in the education and compliance system combines to degrade the immune system until a catastrophic decline takes place and the symptoms of PANS or PANDAS arise. It is a cascade effect, not one cause by itself but several over a period of time which weakens the blood brain barrier and causes idiopathic mild inflammation of certain brain centers.
Acute phases seem to be alined with natural change in brain development at 4-5, 7-8, 14-17. Currently about 1 in 200 children are diagnosed correctly. This means that there is a vast amount of under reporting, misclassification and misdiagnosis.
This is a very simplistic way to look at the events, just because it is simple does not mean that it not true: Recall Occam's razor in science, "For each accepted explanation of a phenomenon, there may be an extremely large, perhaps even incomprehensible, number of possible and more complex alternatives. Since failing explanations can always be burdened with ad hoc hypotheses to prevent them from being falsified, simpler theories are preferable to more complex ones because they are more testable." Or as Ptolemy, a famous early philosopher (c. AD 90 – c. AD 168) stated, "We consider it a good principle to explain ANY phenomena by the simplest hypothesis possible."

Treating the Parents

As part of the healing process we have found that it is just as important for the parents to receive treatment for anxiety and stress. Many suffer from PSTD and the not being listened to by doctor syndrome. They have developed coping mechanisms, may self medicate and be overly combative. After all the genetic imperative is to pass on only good genes and to improve upon the pattern, to live the dream, rather than witness a decline.

WHAT IS PANS AND PANDAS?



Bubble illustration showing how liquids mimic colonies forming masses and also Bio film(s)

We work extensively with families who have children classified as suffering from ASD, ADHD, OCD.

In 2012 we began to record a number of children who did not ‘fit’ into the classic pathology as defined by this diagnosis.

We noticed that children who had been quite ‘normal’ up until a certain point began suddenly to exhibit a range of ‘abnormal’ behaviors. These behaviors had no explicable causation on the surface. A deeper examination of the children's health history revealed a

pattern of chronic sinus, ear or throat infections and subsequent treatment with antibiotics or treatment for acute conditions with antibiotics prior to the age of three. This appeared to be linked with changes in the classical maturation of the brain. Ages 4-5 years Ages 7-9 years and ages 13-17.

So we began to classify the true cause of symptoms/illness. The complex health concerns that are often missed. Sources of illness again often missed or obscured, the underlying root issues, underlying genetic variants, metabolic abnormalities, and environmental contributors/exposures, analyzing both laboratory and anthropomorphic data.

At the same time and working as part of multi disciplinary teams we became aware of the Western medical establishment beginning to define PANS and PANDAS.

So what is PANDAS? “Pediatric Autoimmune Neuropsychiatric Syndrome” PANDAS removed the syndrome and replaces it with the term Disorders Associated with Streptococcus.”

Definition PANS

In simple terms: PANs describes a situation where an infectious pathogen is able to trick a child’s immune system into attacking part of a child’s own brain called the basal ganglia. This leads to a child developing abrupt onset OCD (obsessive-compulsive disorder) and other symptoms.

Definition PANDAS

In simple terms: PANDAS describes a situation where an infectious pathogen identifies in the Strep family is able to trick a child’s immune system into attacking part of a child’s own brain called the basal ganglia. This leads to a child developing abrupt onset OCD (obsessive-compulsive disorder) and other symptoms.

PANS Pathology

It is important to note the difference, in PANS the onset maybe acute and rapid. If addressed quickly then it may vanish just as quickly unless there has been a deeper activation of the brains own autoimmune system.

PANDAS Pathology

In the case of PANDAS, generally the use of an incorrect anti biotic has driven the infection deeply into the child’s system with longer and more devastating results.

SYMPTOMS OF PANS AND PANDAS

In the beginning the condition is usually diagnosed by observation of behavioral issues. At this moment these consist of:

I. Sudden onset OCD, which can manifest as an eating disorder

II. General anxiety and/or separation anxiety

III. Emotional lability (sudden unexplained mood changes)

IV. Aggression, irritability, and oppositional behaviors

V. Behavioral regression (baby talk, drawing like they did when they were younger)

VI. Sudden drop in school performance

VII. Sensory/motor abnormalities (decreased handwriting skills or tics)

VIII. Somatic signs and symptoms (bedwetting, sleep disturbances)

As mentioned the rapid onset of these symptoms without any casual family factors may lead to further investigation.

PANS AND PANDAS BRAIN FUNCTIONS

From the behavioral presentations we can begin to build a matrix of likely avenues of investigation: Various areas of the brain have been shown by studies to be involved in certain conditions. Being involved does not mean that they are responsible for the conditions. They may or may not be. Long term or chronic inflammation certainly will affect the intrinsic development of the neural pathways. Neurons the fire together wire together. This may set up life long patterns which become harder to reverse the longer they are in place.

OCD

Prefrontal cortex (orbito-frontal and anterior cingulate cortexes), basal ganglia, and thalamus are involved in the pathogenesis of obsessive-compulsive disorder (OCD).

ANXIETY

Amygdala appears key in modulating fear and anxiety. Patients with anxiety disorders often show heightened amygdala response to anxiety cues. The amygdala and other limbic system structures are connected to prefrontal cortex regions.

AGRESSION

Aggression is controlled in large part by the area in the older part of the brain known as the amygdala The amygdala is a brain region responsible for regulating our perceptions of, and reactions, aggression and fear.

MOTOR SKILLS

The frontal lobe is responsible for initiating and coordinating motor movements; higher cognitive skills, such as problem solving, thinking, planning, and organizing; and for many aspects of personality and emotional makeup

LANQUAGE

Temporal lobe: controls memory, hearing, and understanding of speech and allows a person to distinguish between sounds and smells.

SOMATIC

The PONS, MEDULLA OBLONGATA, BRAIN STEM

The Pons is responsible for coordinating the activities of the urinary sphincters and the bladder while the Medulla regulating several basic functions of the autonomic nervous system, including respiration, cardiac function, vasodilation, and reflexes like vomiting, coughing, sneezing, and swallowing.

The Benefit of Developing the Map

The benefit of building this matrix is that we can begin to target the organ feed-back loops that critically affect the operational integrity of the brain's system. We can begin to develop strategies which are both effective and cost effective. We focus less on the actual behavioral symptoms themselves rather more on the underlying causations.

Road Map

To arrive at a destination it is a good idea to define where you are going, determine the optimal route given your resources and plan according. Most people do not plan to fail, they fail to plan. What gets measured gets fixed. The territory is not the map, the map is not the territory and it is not the experience of being there. These are all memes that are worth remembering as you undertake the journey:

Selecting a Therapist or Guide

There is a famous saying that doctors bury their mistakes: Quite literally true. It is also true that if you go to a new place then it useful to have someone who has experience of the terrain to help guide you. They are not in charge of the journey **YOU ARE**. Make sure to ask them about failures. There are many successful case studies where the children have fully recovered. There are just as many reasons why, some obvious and some not so obvious.
Be prepared to share your experiences with others. Find a guide that you can communicate with honestly and effectively.

GENETICS

What is MTHFR?

You may have seen the abbreviation “MTHFR” pop up in recent health news. It might look like a curse word at first glance, but it actually refers to a relatively common genetic mutation.

MTHFR stands for methylenetetrahydrofolate reductase. It’s getting attention due to a genetic mutation that may lead to high levels of homocysteine in the blood and low levels of folate and other vitamins.

There’s been concern that certain health issues are associated with MTHFR mutations, so testing has become more mainstream over the years.

Variants of the MTHFR mutation

A person may have either one or two mutations — or neither — on the MTHFR gene. These mutations are often called variants. A variant is a part of a gene’s DNA that’s commonly different, or varies, from person to person.

Having one variant — heterozygous — is less likely to contribute to health issues. Some people believe having two mutations — homozygous — may lead to more serious problems. There are two variants, or forms, of mutations that can occur on the MTHFR gene.

Specific variants are:

C677T. About 30 to 40 percent of the American population may have a mutation at gene position C677T. Roughly 25 percent of people of Hispanic descent, and 10 to 15 percent of Caucasian descent, are homozygous for this variant.

A1298C. There’s limited research regarding this variant. Available studies are generally geographically or ethnic-based. For example, a 2004 study focused on 120 blood donors of Irish heritage. Of the donors, 56, or 46.7 percent, were heterozygous for this variant, and 11, or 14.2 percent, were homozygous.

It’s also possible to acquire both C677T and A1298C mutations, which is one copy of each.

Gene mutations are inherited, which means you acquire them from your parents. At conception, you receive one copy of the MTHFR gene from each parent. If both have mutations, the risk of having a homozygous mutation is higher.

Symptoms of a MTHFR mutation

Symptoms vary from person to person and from variant to variant. If you do a quick internet search, you'll likely find many websites claiming MTHFR directly causes a number of conditions.

Keep in mind that research around MTHFR and its effects is still evolving. Evidence linking most of these health conditions to MTHFR is currently lacking or has been disproven.

What is the COMT gene?

The COMT gene provides instructions for making an enzyme called catechol-O-methyltransferase. An estimated 20-30% of Caucasians of European ancestry have a COMT gene variation which limits the body's ability to remove catechols (a specific type of molecule that includes dopamine, norepinephrine, estrogen, etc.) by 3-4 times. This "slow" variation of the COMT gene is called Met/Met, AA, or +/+. COMT is also associated with greater levels of cortisol and HPA axis dysfunction (which is largely responsible for the body's ability to calm itself and de-stress.

Because of the effects that COMT has on hormones, it directly affects stress reactivity, health, and well-being. Interestingly, those with this gene appear to experience both negative and positive emotions more strongly. For example, those with the COMT gene variation Met/Met tend to be more neurotic and have lower stress resiliency. However, in one study people with the Met/Met variation generated almost similar amounts of positive emotion in response to a "bit pleasant event" as people with the no variation (Val/Val) did from a "very pleasant event."

Should we test?

We strongly recommend conducting two types of test prior to commencing a treatment protocol.

What are some of the benefits of genetic testing for inherited susceptibility syndromes?

There can be benefits to genetic testing, regardless of whether a person receives a positive or a negative result.

An informative negative test can provide the person with peace of mind that a harmful gene variant was not inherited.

A positive test result provides the person an opportunity to understand and, in some cases, manage their risks.

For people who are already diagnosed with a condition, results of genetic testing may help them make decisions about their treatment and understand their risk for other issues.

Genetic testing provides an opportunity for family members to learn about their own susceptibility risks.

Additionally doing a PGx test identifies potential hazards and can help avoid potentially harmful side effects from drugs. With insight derived from pharmacogenetic testing, healthcare providers may decrease the need for "trial-and-error" dosing and might substantially reduce the risk Adverse Drug Events (ADEs).

I. CYP2D6 is the best-studied drug-metabolizing enzyme and affects 25% of all prescription drugs.

II. CYP2C9 acts on 15% of drugs in clinical use.

III. CYP2C19 acts on 15% of drugs in clinical use

Other Types of Tests

If you are uncomfortable with Genetic Testing then there are other forms of bio-energetic tests available. These are not welcomed by the Western Medical Model but none-the-less valid in the hands of the right practitioner. One example is MSA Bio Meridian Stress Analysis Testing.

LAB WORK

Basic labs

These should include

I. Strep throat culture, 48-hour culture and/or perianal culture

II. Bacteria & Virus Blood Work:

III. Anti-Streptolysin (ASO)

IV. Anti DNase B

V. Streptozyme

VI. Mycoplasma Pneumoniae

VII. Pneumococcal Antibody

VIII. Epstein Barr Virus Panel

IX. Coxsackie A & B Titers

X. Lyme Disease and co-infections: Lyme Western Blot & Elisa, Babesia microti & duncani, Bartonella, B. Miyamotoi, Ehrlichia, Anaplasma

XI. HHV-6

Immune System & Autoimmune Testing:

I. IgE Level

II. IgA, IgG, IgM

III. IgG (subclass 1, 2, 3, 4)

IV. Streptococcus Pneumoniae Serotypes

V. CBC

VI. ANA

Further Testing:

I. Ferritin

II. Serum Copper

III. B-12

IV. Vitamin D

V. Plasma Amino Acids

VI. Organic Acids Test

VII.Stool Testing

VIII.Free T3 & T4 and TSH (Thyroid)

Cunningham Panel:

The purpose of the Cunningham Panel™ is to provide laboratory results that assist physicians in diagnosing infection-induced autoimmune neuropsychiatric disorders. The 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.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 antigen. 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.

Some controversy exists around the effectiveness of this panel but mainly due to intra professional politics. The basic science is sound and may assist in the “proving” stage of diagnosis.

Additional Testing

Micro Nutrient Panel Testing from Spectral Cell

SpectraCell's Micronutrient test provides the most comprehensive nutritional analysis available by measuring functional deficiencies at the cellular level. It is an assessment of how well the body utilizes 31 vitamins, minerals, amino/fatty acids, antioxidants, and metabolites, while conveying the body's need for these micronutrients that enable the body to produce enzymes, hormones, and other substances essential for proper growth, development, and good health. Repletion supplementation recommendations can then be are made of the basis of need.

The test measures the functional level and capability of micronutrients present within white blood cells, where metabolism takes place and where micronutrients do their job—thus taking a person's biochemical individuality into account. Unlike static serum measurements, which only assess the concentration of nutrients present outside of the cell (extracellular) and only provide a glimpse of your health, SpectraCell's Micronutrient test is a long term assessment (4-6 months) that addresses the functional impact (performance) of micronutrients—what really matters.

Blood Draws

As many children and adults do not like blood draws it maybe important to consider getting enough a single sitting to be able to satisfy the overall testing demands or scheduling two sittings six months apart.

The Rational for Testing

In large part the rational for testing to establish the basis for a confirmed diagnosis of a syndrome disease or illness which can then be treated and paid for by insurance companies. Probably more importantly is the acknowledgement by the Educational system of the diagnosis thus they are forced to into allocating the appropriate resources.

DIET

This is a highly charged topic and needs to addressed carefully:

We see many cases of ARFID “Avoidant and restrictive food intake disorder (ARFID) and Body Dysmorphia. For many, food restrictions are firmly rooted in OCD, a primary PP symptom; there are often fears of contamination, vomiting, choking. Another symptom of PANS PANDAS is sensory processing issues; this can affect eating due to swallowing and texture issues. PANS PANDAS patients can also have distorted body image. This can happen especially in patients who have PANS PANDAS for several years, so it is seen more often in older patients, but it can happen in younger patients.

The Gut

Typically we see low motility and mobility of organ functions within the abdominal cavity: Stool varies between constipation and diarrhea or a regular basis. Distention of the stomach due to underlying imbalances is also quite common. The microbiome of each child is different but broadly fits into three categories. Some respond well to additional probiotics others don’t.

Sugar Craving

There is a generalized conditionality to sugar dominance in the diet. This is driven by two factors: The first is an overgrowth of fungus and the absence of one of the most important players in the human gut is *Bacteroides thetaiotaomicron* (*B. theta* for short), a bacterial species that’s typically found in individuals who enjoy fiber-rich diets and maintain a healthy weight. In overweight and obese people, on the other hand, bacteria in the Bacteroides group are often far scarcer. Although having B. theta around isn’t a guarantor of health and longevity, it’s thought that these bugs confer a few benefits by fermenting the dietary fiber found in fruits, vegetables, whole grains, and beans into nourishing molecules that the human body can’t make on its own. B. theta produces a protein called Roc—an acronym for “regulator of colonization.” The aptly-named Roc confers the ability to establish residence in, or colonize, a specific locale, like the large intestine; without Roc, B. theta can get flushed out of the system.

PreBiotic and Probiotics

Simply put a Prebiotic is a most likely to be a fermented food which acts upon the Small Intestine which is where most to the action is in terms of ABSORPTION of minerals, fats and nutrients from food. Probiotics live mainly in the large intestine which is responsible for elimination and the reabsorption of water and minerals. It is estimate that there are over 1500 species of bacterium in the large intestine.

Probiotic Meal Suggestions

These “good" bacteria have been linked to better digestive health, immunity, mental well-being, and even weight control. By now, you’re probably well aware that there are plenty of probiotic options beyond yogurt. But sometimes sneaking them into your daily diet can be a challenge. To help you out, here are five super simple meal ideas that incorporate a probiotic-rich food.

Kefir breakfast bowl

Beautiful breakfast bowls are all the rage on Pinterest and Instagram. For a healthy, probiotic twist on this trend, build yours with kefir, a fermented milk beverage, as the base. (If you’re dairy-free there are plant milk versions, like coconut milk kefir, that contain the same probiotic benefits.) Stir in fresh grated ginger, ground cinnamon, or both! Top with sliced fruit, chopped nuts, seeds (like chia, sesame, or sunflower), and toasted old-fashioned rolled oats.

Kimchi omelet

Kimchi is a staple in Korean cuisine, and a probiotic superstar thanks to the fermented combo of veggies and seasonings. For an easy way to fit it in add it to your morning meal, make a flavorful, probiotic-packed omelet. First sauté sliced mushrooms and fresh spinach in olive oil for a few minutes. Then add eggs or egg whites and a quarter cup of kimchi. Allow the eggs to set, and then carefully bring one side to the other, folding the omelet in half.

Salmon sauerkraut lettuce cups

For a quick lunch, start by laying out three large outer Romaine leaves. Add an ounce of either canned, baked, or grilled wild salmon to each. Top each lettuce cup with minced red onion, a spoonful of hummus, and a dollop of sauerkraut. Or replace the lettuce with one slice of toasted whole grain or healthy gluten-free bread.

Pickle-y tuna salad

Pickles can be a great probiotic option. But to reap the digestive and health benefits, be sure you grab a jar that says "fermented" (as opposed to "pickled"). Create a tasty dish by mixing tuna with a generous portion of chopped pickles, a tablespoon of balsamic vinegar, half a teaspoon of dried Italian herb seasoning, plus a teaspoon of spicy brown mustard, and lemon juice. Serve over a bed of your favorite greens, topped with other veggies like

cucumber, grape tomatoes, and bell pepper. Add a little extra crunch with a few tablespoons of slivered almonds or sunflower seeds.

Black bean tacos with fermented salsa

Fermented salsa is one of our favorite new probiotic finds. Look for it in health food stores near the sauerkraut and other fermented veggies. To use it in a meal, sauté sliced onions and bell peppers in low sodium organic vegetable broth over medium heat. Fill either three lettuce cups or two whole corn tortillas with half a cup of black beans. Top with onions, peppers, avocado slices or fresh guacamole, and, of course, the salsa!

Pre and Probiotics Foods

These are all the rage, thanks to a wealth of new research suggesting that consuming "good" bacteria can aid digestion, keep you regular and boost your immune system. But probiotic foods are nothing new—they've been around for thousands of years and are a staple of traditional cuisines around the world.

And it's well worth branching out from yogurt. "Different species of bacteria flourish in different fermented foods, and they offer a spectrum of benefits," explains Justin Sonnenburg, PhD, associate professor of microbiology and immunology at Stanford University and author of The Good Gut. "So it's smart to eat a variety of fermented foods." Check out this sampling of ancient probiotic powerhouses.

Curtido

A Central American cousin of sauerkraut, this fermented salsa from El Salvador usually consists of cabbage, onions and chilies, among other vegetables. It's traditionally served with pupusas (thick, handmade corn tortillas), but curtido also makes a tasty taco filling and topping for grilled chicken, fish, and rice and beans. Or you can simply give a bowl of chips a probiotic kick with fermented salsas sold by brands like Wildbrine.

Kvass

Native to Russia, this fermented grain drink is traditionally made by adding yeast to brown bread that's been soaked in water. The kvass at your local health-food store is likely made from beets or carrots instead of bread. So in addition to probiotics, kvass has all the vitamins in fresh-pressed beet or carrot juice but with a fraction of the sugar, owing to its carb-hungry microbes. (For example, Zukay Beet Kvass contains just 4 grams of sugar per 6-ounce serving, while commercial beet-juice blends typically have more than twice that.)

Can't handle drinking it straight? Try adding small amounts to salad dressing or using it in no-cook recipes (cooking kills the good bugs) in place of vinegar.

Aged Cheese

One more reason to love Roquefort and Gruyère: "The same bacteria and fungi that give aged cheeses incredible flavor profiles can add great microbial diversity to your diet," Sonnenburg says. Just use caution with aged cheeses made from raw milk; while harmful bacteria may be reduced in the aging process, pregnant women and the immunocompromised should still steer clear.

Sauerkraut

In its simplest form, sauerkraut is shredded cabbage fermented in salted water. The tart condiment is packed with Lactobacillus plantarum, a powerful probiotic, which may help fight cancer and lower cholesterol. Look for raw (not pasteurized) varieties in the refrigerated section of your supermarket.

Kefir

This fermented milk beverage (originally developed in the Caucasus Mountain region of Eurasia) tastes like liquidy yogurt but contains a more diverse range of bugs—typically at least 10 species (compared with yogurt's usual two to four). It's made using kefir "grains," a starter culture that often includes a type of yeast that may protect against gastrointestinal distress, as well as a bacteria thought to ease constipation and another that can help alleviate inflammatory gut disorders. If you're lactose intolerant, you might find kefir easier to digest than milk because its probiotics consume much of the problematic sugar before you drink it.

Kombucha

This trendy, fizzy fermented tea originated in China around 220 BC as a health elixir. Today it's the subject of many claims (detoxifying! Boosts energy!) that are hard to prove. But it may have some healing powers: An animal study published in Pharmaceutical Biology in April found that kombucha lowered LDL cholesterol and improved liver and kidney function. "Make sure the label says ‘raw' and that the formula contains little or no added sugar," suggests Jayson Calton, PhD, co-author of The Micronutrient Miracle, who prefers the brand LIVE Kombucha Soda.

Kimchi

Because it's made from a variety of veggies and seasonings (including napa cabbage, garlic, chilies, ginger and fish sauce) and ferments for a long time, this spicy and pungent Korean staple contains a very diverse assortment of bugs. "Of all probiotic foods, kimchi probably ranks number one," says Raphael Kellman, MD, a New York City integrative physician and author of The Microbiome Diet.

Pickles

They can be loaded with probiotics, but choose carefully. Many are pasteurized and jarred in white vinegar, which gives them a piquant taste but no friendly microbes. Instead, you want pickles that have been fermented in brine— the way they were made in ancient Mesopotamia. One study on Lactobacillus brevis, a bacteria from fermented pickles, found that regular intake significantly reduced incidence of the flu. You'll find traditional pickles in the refrigerated section of the grocery or health-food store. The label should say "naturally fermented," "nonpasteurized" or "contains live cultures," advises Michelle Schoffro Cook, PhD, author of The Probiotic Promise. Look for fermented green beans, cauliflower and beets, too—each packs a wide array of vitamins, minerals and probiotics.

Miso

A seasoning paste made from fermented soybeans, miso might deserve some credit for the famous longevity of the Japanese. Animal research suggests it may protect against cancers of the breast, colon, liver and lungs. The longer soybeans are left to ferment (sometimes with rice, barley or other ingredients), the more potent their health perks. (Red and brown varieties are typically fermented longer than white.) Try stirring miso into rice, dressings and sauces. Sadly, miso soup isn't a good source of probiotics, because it's cooked. Sensitive to soy? A company called South River offers varieties made with chickpeas instead.

COMPARING TREATMENTS FOR PANS/PANDAS

The National Institute of Mental Health recognizes antibiotics, steroids, IVIG, and plasma exchange as treatments for PANS/PANDAS. These are research-backed treatment initiatives and options. We have included experiential options which tend to be less invasive.

The list is not ranked by order of effectiveness nor is a recommendation for any treatment. It is not a complete list of the possible effects or side effects.

Read below about the following PANDAS treatment options, complete with our grade on how effective it is, how much research is behind it, potential for side effects, estimated cost, and if it's typically covered by insurance.

Cognitive Behavioral Therapy

Cognitive behavioral therapy helps families grapple with a child's behavioral changes. Though not always effective by itself, it can greatly improve quality of life while the child has OCD.

Here, children may learn to name their OCD, argue against their OCD, and confront their fears in a controlled manner.

Cognitive behavioral therapy is shared between the child and parent. Both learn to cope through stress-reducing rituals and avoidance strategies.

One clinical trial found children with PANDAS saw a 49% reduction in symptoms after cognitive behavioral therapy.

If a child exhibits symptoms of OCD after an infection has gone away, or if a child exhibits residual symptoms after the fact, cognitive behavioral therapy is definitely worth looking into.

Effectiveness: High

Level of Research Available: Moderate

Potential for Side Effects: None

Estimated Cost: High ($150-$300 per 45 minute sessions)

Typically Covered by Insurance: Yes

CranioSacral Therapy (CST)

CST was pioneered and developed by osteopathic physician John E. Upledger following extensive scientific studies from 1975 to 1983 at Michigan State University, where he served as a clinical researcher and Professor of Biomechanics. CST is a gentle, hands-on method of evaluating and enhancing the functioning of a physiological body system called the CranioSacral system - comprised of the membranes and cerebrospinal fluid that surround and protect the brain and spinal cord.

Effectiveness: High

Level of Research Available: Moderate

Potential for Side Effects: None

Estimated Cost: High ($150-$300 per 45 minute sessions)

Typically Covered by Insurance: No

Intravenous Immunoglobulin (IVIG)

Intravenous immunoglobulin (IVIG) contains antibodies that are used to treat immune system disorders. Since PANS and PANDAS are autoimmune disorders, IVIG helps ameliorate the confused immune response the infection or toxin has caused.

IVIG is typically made up of 95% unmodified immunoglobulin G, from upwards of a thousand human blood donors.

Early studies suggested IVIG was an effective PANDAS treatment.

It is still unknown how exactly IVIG can treat PANDAS, but the FDA has approved it for treating other immune function disorders in minors.

IVIG likely reduces or neutralizes the confused antibodies (that are attacking the brain) in your child's system, but it doesn't decrease the amount of confused antibodies your child's body still makes.

Side effects of IVIG include headache, fatigue, irregular body temperature, and nausea. It is also a very invasive procedure.

Effectiveness: Moderate

Level of Research Available: High

Potential for Side Effects: Low

Estimated Cost: Very High ($10,000-$25,000)

Typically Covered by Insurance: Sometimes (depending on where you live and what the diagnosis is). Organizations are currently working with legislators to pass a law which would prohibit insurance companies from denying coverage for IVIG just because the diagnosis is PANS or PANDAS.

Plasmapheresis

Plasmapheresis (AKA plasma exchange) is a process of cycling a patient's blood through a machine where the blood cells are separated from the plasma (the liquid part of blood). The machine replaces the patient's plasma with new plasma.

This treatment is viable because the plasma carries antibodies different to the ones wrongly attacking the child's brain.

One clinical trial showed some level of improvement in every single PANDAS patient who had plasmapheresis therapy. Upon follow up, PANDAS symptoms improved 78% on average.

Plasmapheresis has been described as "essential" in PANDAS treatment. However, it is invasive and may be uncomfortable.

Effectiveness: High

Level of Research Available: High

Potential for Side Effects: Low

Estimated Cost: Very High ($1000-$2000 per procedure)

Typically Covered by Insurance: No

Tonsillectomy

In a few case reports, tonsillectomy (removal of tonsils) stopped PANDAS in its tracks.

A 2018 literature review found weak support for this procedure.

Likely, a tonsillectomy may treat PANDAS only because it may treat a strep infection. Since it helps avoid future strep infections, it may give parents peace of mind.

Effectiveness: Uncertain

Level of Research Available: Low

Potential for Side Effects: Moderate

Estimated Cost: Very High ($5400)

Typically Covered by Insurance: Yes

Antibiotics

Antibiotics could be the right option for your child, especially in the early stages. It is probably the most widely-used treatment option, but only because antibiotics (like penicillin and azithromycin) have the most robust research.

A small-scale study showed that antibiotics are effective in two-thirds of moderate PANDAS cases.

A recent scientific review revealed that antibiotic therapy is a well-established PANDAS treatment when a strep infection is ongoing.

However, if PANDAS persists after an infection is dealt with, antibiotics may not be the right choice.

If your child undergoes antibiotic therapy, it may be wise to counter-treat with probiotics, to maintain your child's immune health. Since antibiotics kill both good and bad bacteria, probiotics may be required to reintroduce good bacteria into your child's gut microbiome, which can affect the immune system. Probiotic counter-treatment can also prevent antibiotic-induced diarrhea.

Effectiveness: Moderate to High

Level of Research Available: Very High

Potential for Side Effects: Low to Moderate

Estimated Cost: Low to moderate ($20 to $200)

Typically Covered by Insurance: Yes

Corticosteroids

Steroid therapy, such as using corticosteroids, has exhibited positive results in some children with PANDAS.

Short bursts of steroids may be the safest and most effective method of corticosteroid therapy. With more than a month of steroid therapy, a child's risk of side effects increases.

Unfortunately, corticosteroids sometimes lead to an increase in aggressive behavior.

Effectiveness: Moderate

Level of Research Available: Moderate

Potential for Side Effects: Moderate

Estimated Cost: Low ($10-$50 per course)

Typically Covered by Insurance: Yes

Nonsteroidal Anti-Inflammatory Drugs (NSAIDs)

NSAIDs alleviate PANDAS symptoms, but not as effectively as other treatments. However, the research is pretty consistent: NSAIDs help with PANDAS.

Since NSAIDs can come with adverse side effects (heartburn, stomach pain, dizziness, itchiness, blurred vision, etc.), we suggest all-natural anti-inflammatories, like curcumin and ginger.

Effectiveness: Moderate

Level of Research Available: Moderate

Potential for Side Effects: Moderate

Estimated Cost: Low (Less than $30 a bottle)

Typically Covered by Insurance: No

Vitamin D

Recent research reveals PANDAS patients are significantly more likely to have a vitamin D deficiency than control groups.

Nine out of ten children with PANDAS may need more vitamin D — whether from their diet, exposure to sunlight, or dietary supplements.

Effectiveness: Moderate

Level of Research Available: Low

Potential for Side Effects: Low

Estimated Cost: Low (less than $30 a bottle)

Typically Covered by Insurance: Yes (with documented vitamin D deficiency listed in the chart)

Anti-Inflammatory Diet & Supplements

Part of “clean living” is eating well. Adopting an anti-inflammatory diet can promote whole-person wellness and strengthen your immune system.

To curb inflammation that is linked to autoimmune disorders (like PANDAS), cut these from your child’s diet:

Dairy

Gluten

Sugar

Preservatives and chemicals

Also, consider natural anti-inflammatories like omega-3 fatty acids, curcumin, and boswellia.

Effectiveness: Moderate

Level of Research Available: Low

Potential for Side Effects: None

Estimated Cost: Low

Typically Covered by Insurance: No

SSRIs

Selective serotonin re-uptake inhibitors (SSRIs) are sometimes used to treat OCD symptoms. Our own clinical experience and research studies have found less than half of PANDAS patients respond well to the treatment.

Examples of SSRIs include: Fluoxetine Fluvoxamine Paroxetine Sertraline

A troubling side effect of SSRIs can suicidal thoughts in children. For this reason, close supervision and communication with a doctor is advisable.

Effectiveness: Low

Level of Research Available: High

Potential for Side Effects: Moderate to High

Estimated Cost: Low (as low as $10 a month)

Typically Covered by Insurance: Yes

Antipsychotics

Antipsychotics have been used to treat PANDAS, but they are not very effective.

Side effects add to complexity.

Effectiveness: Very Low

Level of Research Available: Low

Potential for Side Effects: Very High

Estimated Cost: Low ($14 a bottle)

Typically Covered by Insurance: Yes

Antihistamines

Antihistamines boost the immune system, reduce inflammation, and help many children sleep. In these ways, antihistamines is a low-cost PANDAS treatment option.

Close monitoring is necessary since some children react badly to antihistamines. They may become more agitated instead of sleepy.

Effectiveness: Moderate

Level of Research Available: Low

Potential for Side Effects: Moderate

Estimated Cost: Very Low ($1 a dose)

Typically Covered by Insurance: Yes

Treat the Strep, PANDAS Might Go Away

Treating strep infections can lead to PANDAS going away. As long as the child is not re-infected with strep, PANDAS may be in your rear view mirror.

Ozone Therapy

In an in vitro study, it was observed that O3 is very effective in reducing the concentrations of Acinetobacter baumannii, Clostridium difficile and methicillin-resistant Staphylococcus aureus in dry as well as wet samples, hence it can be used as a disinfectant. Ozone was effectively used as an antibacterial agent to treat oral infections caused by Actinomyces naeslundii, Lactobacilli casei and Streptococcus mutans. Might be very useful for clients who have extreme sensitivity to antibiotics.

Effectiveness: Moderate

Level of Research Available: Low

Potential for Side Effects: Moderate

Estimated Cost: Moderate ($60 per session)

Typically Covered by Insurance: No

Hyperbaric oxygen therapy

Hyperbaric oxygen therapy is used to treat several medical conditions. And medical institutions use it in different ways.

Your body's tissues need an adequate supply of oxygen to function. When tissue is injured, it requires even more oxygen to survive. Hyperbaric oxygen therapy increases the amount of oxygen your blood can carry. With repeated scheduled treatments, the temporary extra high oxygen levels encourage normal tissue oxygen levels, even after the therapy is completed. In cases where there has been a depletion in the blood brain barrier with associated loss of grey matter this therapy has proven to be very useful.

Effectiveness: Moderate

Level of Research Available: Low

Potential for Side Effects: Small

Estimated Cost: Moderate ($60 per session)

Typically Covered by Insurance: No

Homeopathic Treatments

Homeopathic Treats differ from western medicine in that they treat like with like rather than adverse; It is more spiritual in nature and use to treat the emotional flow of energy within the body. Well documented success stories from Europe indicate that it worth exploring:

Effectiveness: Moderate

Level of Research Available: Low in USA High in Europe.

Potential for Side Effects: Small

Estimated Cost: Moderate ($60 per session)

Typically Covered by Insurance: No

Acupuncture and Chinese Herbs

Generally speaking Chinese medicine does not treat conditions rather the person themselves. There are a growing number of practitioners who claim to have helped reversed the condition.

Effectiveness: Moderate

Level of Research Available: Low in USA High in Asia.

Potential for Side Effects: Limited

Estimated Cost: Moderate ($90 per session)

Typically Covered by Insurance: No

Essential Oils

According to NIH the Essential oils of oregano, peppermint, orange or lemongrass kill most strains of fungal and bacterial infections. This maybe as good adjunctive or primary therapy for children highly sensitive to antibiotics and to prevent subsequent reinfection. The raindrop technique has proven to be effective and non invasive.

Effectiveness: Moderate

Level of Research Available: Low in USA

Potential for Side Effects: Limited

Estimated Cost: Moderate ($30 per bottle)

Typically Covered by Insurance: No

Healy Micro Frequency Device

Micro Frequencies are a way to balance the subtle energy field which surrounds the body. Just like Reiki for indeed Acupunture. Useful in children that are scared of needles. Used to support balancing of the whole body not to treat a specific condition.

Effectiveness: Moderate

Level of Research Available: Low in USA

Potential for Side Effects: Limited

Estimated Cost: Expensive

Typically Covered by Insurance: Maybe

Summary

There are an increasing number of potential solutions which may give rise to confusion and inability to choose: We always strongly advise that the child be wholly involved in the selection of treatments that they find acceptable: It is important tot remove that children are more than a collection of symptoms: The issues need to be addressed on multiple levels. Physical, Emotional, Neurological, and Spiritual (PENS) when they are everybody benefits.

AT SCHOOL

Most PANS PANDAS students require individualized school accommodations to some degree, ranging from an Individualized Education Plan (IEP) to a 504 plan, to an Individualized Health Care Plan (ICHP) to non-formalized supports built into classroom friendly strategies.

Individualized Education Plan (IEP)

The accommodations vary depending on the student's symptoms and severity as well as from flare to flare. Each symptom can cause its own set of difficulties at school and when combined with several symptoms, even more significant challenges must be addressed. There is neither a one size fits all presentation of symptoms nor a one size fits all set of accommodations.

Due to the changing nature of symptoms and the relapsing and remitting course of PANS, ensure plans are flexible. Plans should be written with the student's worst days in mind while hoping for the best days. A student may initially present with one or more primary symptoms, which may resolve with treatment only to be replaced with a new set of symptoms or different manifestations of the initial symptoms. Academic performance and attendance can vary widely during exacerbations.

One month, a student may be in a debilitating flare requiring several supports but later in the school year require significantly less only to relapse again. Not all PANS students return to baseline between flares, requiring year-round accommodations even while not in an active flare. Student performance and needs can vary day-to-day and week-to-week.

Other Health Impairment (OHI) is the condition that most PANS students qualify for an IEP. Students may be eligible for an IEP under different categories as well depending on that student's symptoms such as specific learning disability (SLD), autism spectrum disorder (ASD) or emotional and behavioral disorder (EBD). However, caution must be taken to not mislabel a student; SLD or EBD may not encompass all of the student's issues by focusing too much on a small portion of symptoms.

Individualized Health Care Plan (ICHP)

Consult with your and School nurse OT for help with plans for Flareups and build a plan that works for the family situation.

ABOUT THE AUTHOR

I truly believe that if I were a young child today I would be diagnosed as being on the spectrum. It is very possible that at certain points that I would have also been diagnosed with PANS. At the age of five I was strongly allergic to penicillin, which meant that it was doing its job, as strange as it may sound to say that. I did not have anaphylaxis. I grew out of most of the issues but still my immune system tends towards being compromised rather than balanced. So it is entirely possible that by doing nothing the child will grow out of the issue. So it is entirely possible that by doing nothing the child will grow out of the issue as I did. Working its way through the stress may benefit the child in ways hard for us to either accept or comprehend. As humans and as parents we need to know when to act, when to support and not enable and how to select our medical advisors and when to leave it to nature to sort out.

I say this with all respect to parents who are coping with the deeper and most profound aspects of this condition. It is for you that I have written this text and please feel free to vent if you so desire or if it pleases you better contribute your voice to the discussion. For me this is not an argument about who is right but a discussion about what is right.

Anthony has been described as a Medical Intuitive, Healer amongst other titles, his first love is the integration of many techniques into healing sessions that honor and respect the inner healing wisdom of his clients. He has published over twenty books on a wide variety of topics.