# PANDAS and PANS 101: What Is It? Why Should I Be Concerned?



### What Does PANDAS and PANS Stand For?

### **PANDAS**

<u>Pediatric Autoimmune</u>
<u>Neuropsychiatric Disorder</u>
<u>Associated with</u>
<u>Streptococcal Infection</u>



Pediatric Acute-onset Neuropsychiatric Disorder



# Common Symptoms found in National Institute of Mental Health Samples (NIMH)

#### **Symptoms During Exacerbations**

- Choreiform movements 95%
- Emotional lability 66%
- School changes60%
- Personality changes 54%
- Bedtime fears50%

- Fidgetiness 50%
- Separation fears40%
- Sensory defensiveness40%
- ► Irritability 40%
- Impulsivity and distraction 38%

### **Comorbid Diagnoses**



- **ADHD 40%**
- **ADD 40%**
- Depression 36%
- Separation anxiety 20%
- Overanxious 28%
- Enuresis 20%
- Anorexia 17%

## Estimated that 1 out of 100 to 200 children in the US have PANS/PANDAS

#### PANDAS DIAGNOSIS CRITERIA

- Presence of OCD and/or tics, particularly multiple, complex or unusual tics
- Age requirement (Symptoms of the disorder first become evident between 3 years of age and puberty)
- Acute onset and episodic (relapsing-remitting) course
- Association with Group A Streptococcal (GAS) infection
- Association with neurological abnormalities

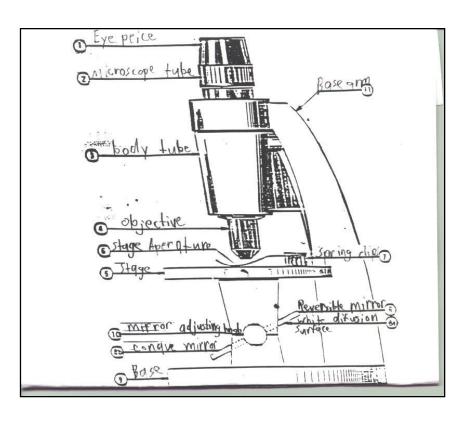


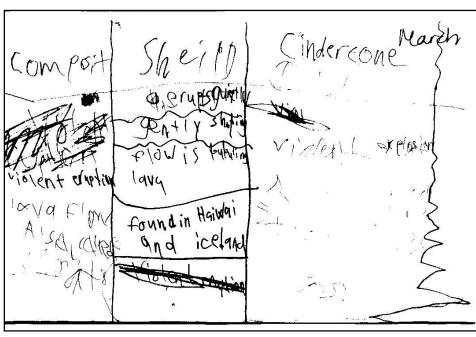
- Young age at onset
  - 6.5 +/- 3.0 years for tics
  - 7.4 +/- 2.7 years for OCD
- Boys out number girls 2.6 to 1

### Dysgraphia is Frequent in Children with these Conditions

**Subject 1: Before Observed Motor Tics** 

**Subject 1: After Observed Motor Tics** 





### PANDAS and PANS are triggered by infections causing and autoimmune attack on the Brain

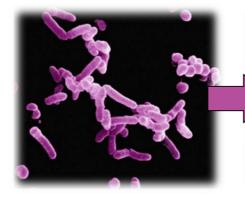


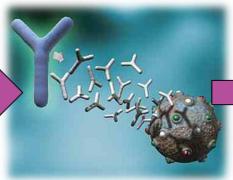
Microbial, Viral, Fungal Infection Occurs

**Body Produces** Antibodies That Recognize Infectious Agent

Antibodies Cross-React With Neurologic Receptors (molecular mimicry)

Reaction Disrupts **Brain Function** (friendly fire)























**Neuropsychiatric Symptoms Including Anxiety,** Aggression, Rage, OCD, Tics, Depression, Hyperactivity, Insomnia, Phobias



# It is Understood that PANDAS/PANS is a Result of Molecular Mimicry

- Molecular Mimicry = "Friendly Fire"
- The Immune System Attacks the Body = autoimmune
- Infections can lead to autoimmune responses with debilitating neuropsychiatric symptoms



### Standard of Medical Care for Neuropsychiatric Disorders



#### 1. Psychotropic Drugs

- Antipsychotics, antidepressants, stimulants and mood altering drugs
- Deleterious side effects and warnings such as
  - Risk of death, suicide, worsening depression, insomnia, aggression, dangerous impulses, mania, mood swings, anxiety
- Prescribing young as 3 years old

#### 2. Psychotherapy

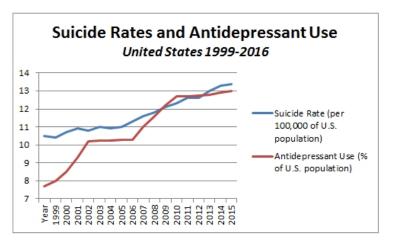
- Cognitive Behavioral Therapy
- Brain stimulation therapy

#### 3. Institutionalization



### MOST FREQUENTLY PRESCRIBED PSYCHOTROPIC DRUGS (2013 DATA)

Xanax (alprazolam), 48.5 million
Zoloft (sertraline), 41.4 million
Celexa (citalopram), 39.4 million
Prozac (fluoxetine), 28.3 million
Ativan (lorazepam), 27.9 million
Desyrel (trazodone HCL), 26.2 million
Lexapro (escitalopram), 24.9 million



Sources: National Institute of Mental Health; Centers for Disease Control and Prevention

### Survey of 1,000+ PANDAS/PANS Parents (Sample of written responses) 1 of 52 financial impact questions

#### What was the financial impact of your child's PANDAS/PANS or autoimmune encephalopathy diagnosis or symptoms

Borrow against 401K; burn through my deceased husband's life insurance money because I can't work full-time and barely have been able to hold onto my part-time job.

pre divorce! Borrow from a high interest lending company

savings exhausted, vacations not taken, etc.

Brink of bankruptcy

Max credit cards

. loss of income when ultimately had to stop working

Lose job

Extreme credit card debt

I no longer work

sold house

We did not lose our home but had to sell our home to move to a less expensive neighborhood

Not test/treat unless it is a covered expense. So, only option is to allow the child to suffer.

I prayit doesn't have to come to this.

drain savings

Exhaust savings

Rework the budget

Move to another city to get proper care

Go fund me, fundraisers,

Broke and in debt

Sold house and bought older cars

Change lifestyle

Skip bills Work a second job

Borrow against life insurance policies

maxed out two credit cards (>\$50,000)

We are close to declaring bankruptcy

Find a part time job in addition to my full time job

Borrowed \$140,000.00 from family and received gifts of \$26,000.00 not kidding

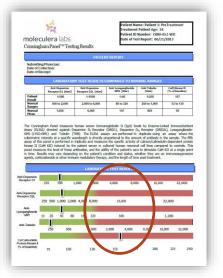
impacted retirement and college savings. Restrict spending on other theings

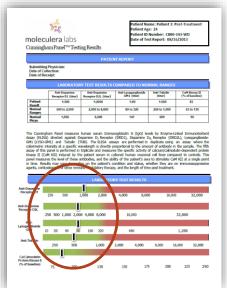
### Case Studies (>200 Similar Case Studies)



#### Case Study #1

24 y/o Male: Presenting symptoms: OCD, tics, decreased appetite with 30 pound weight loss, inability to concentrate, sensory abnormalities, emotional lability, behavioral regression, separation anxiety, et al.

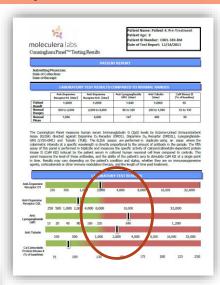


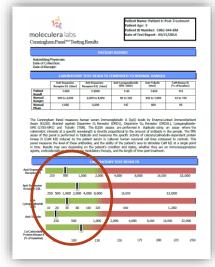


Treatment: Patient treated with IVIG and plasmapheresis resulted in symptom reduction

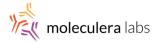
#### Case Study #2

9 y/o Female: obsessivecompulsive behaviors, verbal tics and "stimming", inability to concentrate, sensory and motor abnormalities, emotional lability, behavioral regression, urinary and sleep problems, dysgraphia, and aggressiveness, Relapsing and remitting in nature

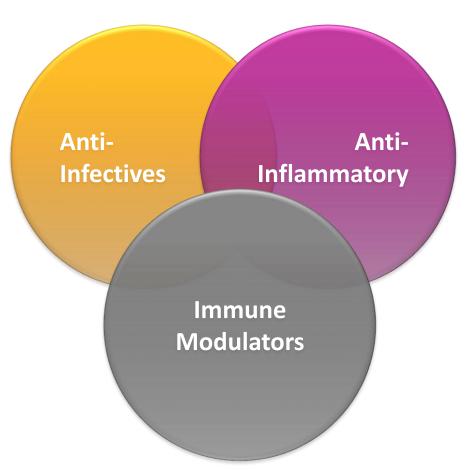




**Treatment:** Patient was treated with azithromycin with rapid improvement in symptoms



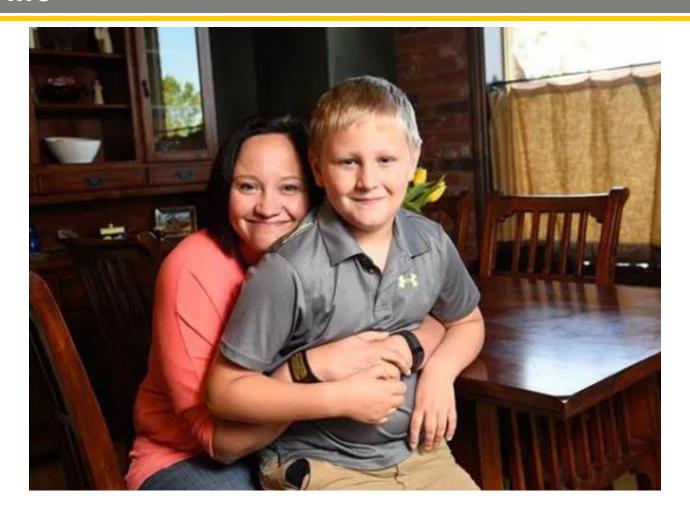
# Treatment Categories for Infection-triggered Autoimmune Neuropsychiatric Disorders of the Brain



- Anti-microbials
- Steroids and NSAIDs
- Plasmapheresis (Plasma exchange)
- Intravenous Immunoglobulins (IVIG)
- Immune modulating medications
- Symptomatic Treatment
  - Cognitive Behavioral Therapy
  - Low dose SSRIs

Effective allopathic, integrative or natural treatments tend to fall into these categories

# "Third-grader's new diagnosis leads to calmer, focused life"



Wendy Elliott and her son, Adam, 9, in their south Oklahoma City home Adam was recently diagnosed with PANDAS, an autoimmune disease, received treatment and got well

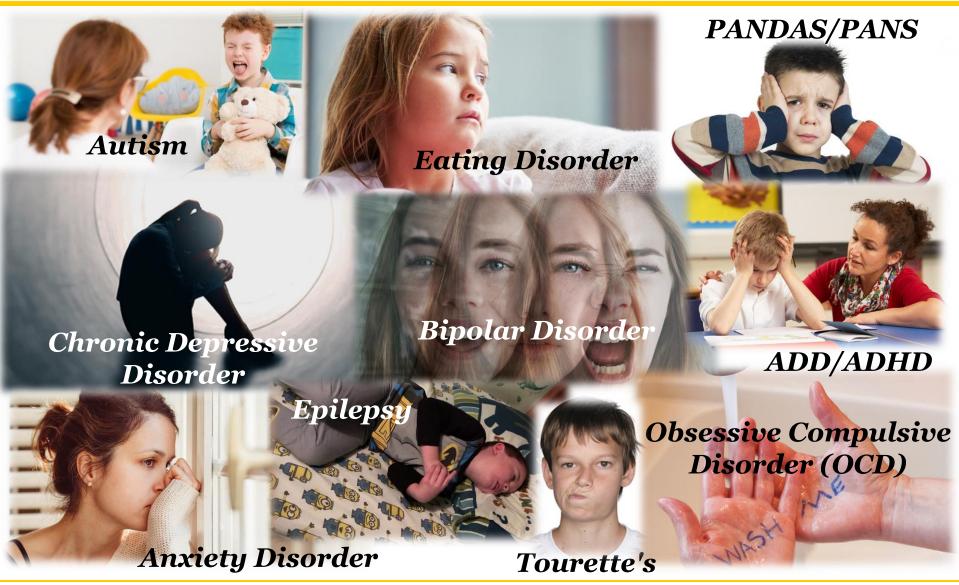
# Why Should I Be Concerned About Testing and Treatment for PANDAS and PANS?



Disease/Disorder	Estimated Prevalence In U.S.
PANS/PANDAS	497,000
Autism	1,263,000
ADHD	8,195,000
Anxiety	6,874,000
Tourette's Syndrome	460,000
OCD	1,118,000
Depression & Bipolar Disorder	4,361,000
Eating Disorder	2,563,000
Epilepsy	559,000
	25,890,000

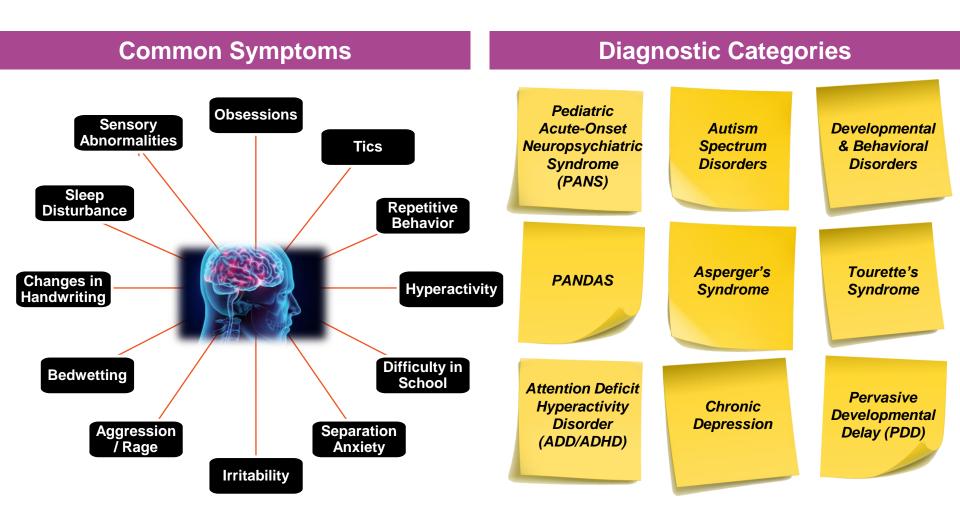
# Over 25 Million Individuals in the U.S. Suffering from Neuropsychiatric Disorders





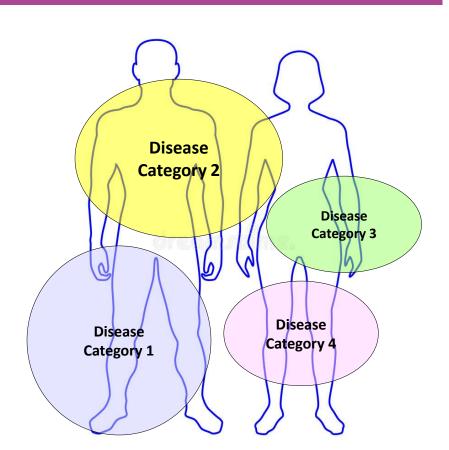
# PROBLEM: Patients are Labeled into Symptom-Based Categories which are Typically Deemed "Incurable"



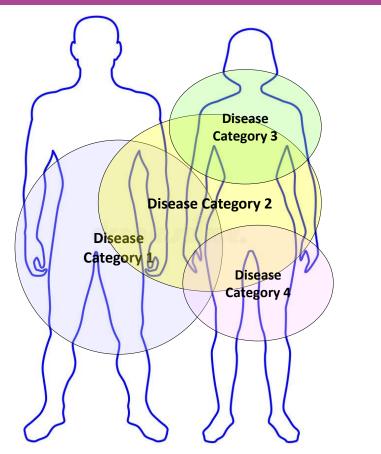


# Complex Diseases and the Challenges of Specialization in Medicine

#### **Categorical View of Disease**



#### **Systemic View of Disease**



Identical "symptoms" can manifest through totally different etiologies

Disease resolution is only possible with an accurate understanding of the etiology



### Tack Laws #1 and #2 (Dr. Sydney Baker)



#### Tack Law #1



- If you are sitting on a tack, the treatment is not two Advil every 3-4 hours
- The treatment for "tack sitting" is "tack removal"
- Search for the root and treat the cause rather than the symptoms

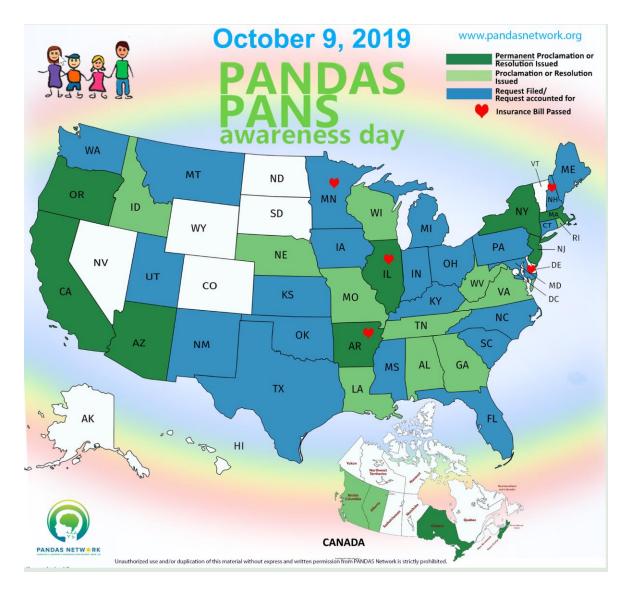
#### Tack Law #2



- If you are sitting on two tacks,
   removing one tack does not eliminate
   50% of the symptoms
- Complex conditions are "complex"
- To be effective, address all the underlying causes for resolution

Correctly diagnosing the root cause for patients with neuropsychiatric symptoms is critical to prescribing the correct treatment

# States Where Insurance Legislation and/or Proclamations Passed







A Precision Medicine Company Diagnosing Neuropsychiatric Disorders Caused by an Autoimmune Response

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