

## **Where is Treatment Headed for Our Children?**

### I. Overview of National Awareness

PANDAS Network.org has grown from 5-10 childhood cases in 2009 to over 2,000 reports in 2013.

Over 100,000 interested viewers and viewers increase by 10,000 nearly every month. Now is the time to take steps to recognition as group. How do we do this?

**Essential:** A **National Registry Project** is essential for PANDAS-PANS cases to be taken seriously by investigators. We need to make our cases visible to researchers! Funds need to be raised.

PANDASNetwork.org is recognized as a National Partner to the NIMH to link to the **Brain Initiative**.

The White House launched a 10 year project. \$100,000 Million funding will be equally distributed among nine different research areas. What Nobel Prize Laureates will/may be researchers?

<http://www.whitehouse.gov/the-press-office/2013/04/02/fact-sheet-brain-initiative>

<http://www.nih.gov/science/brain/> Participate in the May Meeting via Phone (no charge)

Watch the PBS Show - Charlie Rose (2013) interview of the Brain Initiative Panel with NIMH Director, Tom Insel.

**Essential: Fill out the Current PANDAS-PANS Survey Effort:** Dr. Jan Tona, Professor of Rehab Science -Univ of Buffalo developed together with Dr. Denise Calaprice-Whitty, Epidemiologist and Dr. Tanya Murphy – reports on onset, symptoms and treatment. <http://pandasnetwork.org/survey/>

**Essential: Uniformity in Diagnostic Scale (NIMH-YALE PANDAS-PANS Scale).** We can help doctors speak our language. Hand it to your doctors ☺

[http://pandasnetwork.org/testing\\_outcome/diagnostic-tests/#PANDAS/PANS Symptom Scale](http://pandasnetwork.org/testing_outcome/diagnostic-tests/#PANDAS/PANS Symptom Scale)

## II. Parent Reports to PANDASNetwork.org

**MAP of U.S. and Abroad** – Self-reported Cases = 1,500

Clusters are seen in communities: NC, VA, CA, MA, PA

Why are there clusters? Anecdotally doctors report it *may be* virulence factors. However, genetics absolutely play a part in it.

**1,000 Parents report average age 4-9 years old: 67%**

1-2=35; 3=65; 4=81; 5=112; 6=99; 7=136; 8=123; 9=105; 10=72; 11=34; 12=44; 13=30; 14=14;  
15=17; 16-18=18; 19-20=8; 21-24=5

Parents report Both OCD and Tics = 29% OCD Only = 48% Tics Only = 23%

Strep reported only = 86%

## III. Report of 200 Families Post Treatment 2 years:

70% maintained improvement for 2 years by using abx only (I am not clear on dosing; but it was at least intermittent use if not continual)

70% maintained improvement for years after one or two IVIG (these cases seemed more severe but it is not clear and abx were needed during convalescent period – dosing is not clear)

70% of 100 families Report of Autoimmune Disease in First/Second Generation of family and Strep related illness

## IV. **Diana's Personal Story** (2 Charts: Cunningham Test measuring improvement over one year; Azithromycin/IVIG improvement)

## V. Why is there vacillation about PANDAS-PANS Treatment?

Blood Brain Barrier Research is new! That it *can* be breached is radical!

Agalliu (UC Irvine) and Cleary (Univ of Minn) points to T-cell 17 induced by strep breaches the BBB (2014)

Schatz (Stanford U) – found proteins (MHCI) that do tag for invaders for immune system attack (2013)

Ransohoff (Cleveland Clinic) – monocytes attach to the cells walls of blood vessels of the BBB and soften it up for T or B cells to get across (2012)

The BBB protects this *most essential center of our brain*. Doctors want to be sure before treating that they are doing the right thing.

**Research pointing to the Basal Ganglia Implied in PANDAS (Cunningham, Swedo, Hornig, Agalliu, Murphy, Trifiletti, Leckman, Najjar, Chugani, R.C. Dale and others)**

**B.G. is a major Switching station:** Reason, problem solving, task flexibility Tourettes and OCD implicated the B.G.

A **major input center** of the basal ganglia is the **Striatum**

**Regulation of dopamine**

**Amygdala** – fear and fight or flight

**Hypothalamus** – parenting and attachment, sleep, endocrine (hormones)

**Thalamus** – disregulation of consciousness and sleep

*Image found under basal ganglia and hypothalamus*



## **VI. Anecdotal Reports**

*List of exacerbation issues that CALM DOWN once treatment has begun. Improvement is dramatic if not entirely within one year with most severe cases even faster for less severe.*

**Treatment (length and dose) needs are usually based on severity. Early treatment is most helpful.**

Kids with gut issues: Celiac or history of tummy cramps, underweight – they have a harder time. (Integrative doctors are often good with this area.)

Histamines (1 allergies and 2 tummy) can cause uptick in symptoms.

Sometimes tonsillectomy/adenoidectomy is wise to do.

Exacerbations occur: loose teeth, sinus inflammation, proximity to other sick kids.

Teeth grinding (bruxism) and Stuttering (apraxia) - in the amygdale

When healing or for a few months post treatment: no big crowds, roller coasters, long nights out. Limit the t.v. and computer if you can. Rest and be together as a family.

This is a time for healing the BBB or the excitatory neurons in the brain....stress, fatigue, illness...all exacerbate healing.

Lastly, it takes time, be patient, they will heal and get support from friends, family, professionals or pandas community.