

Autoimmune Brain Disorders: A Patient Advocate Perspective

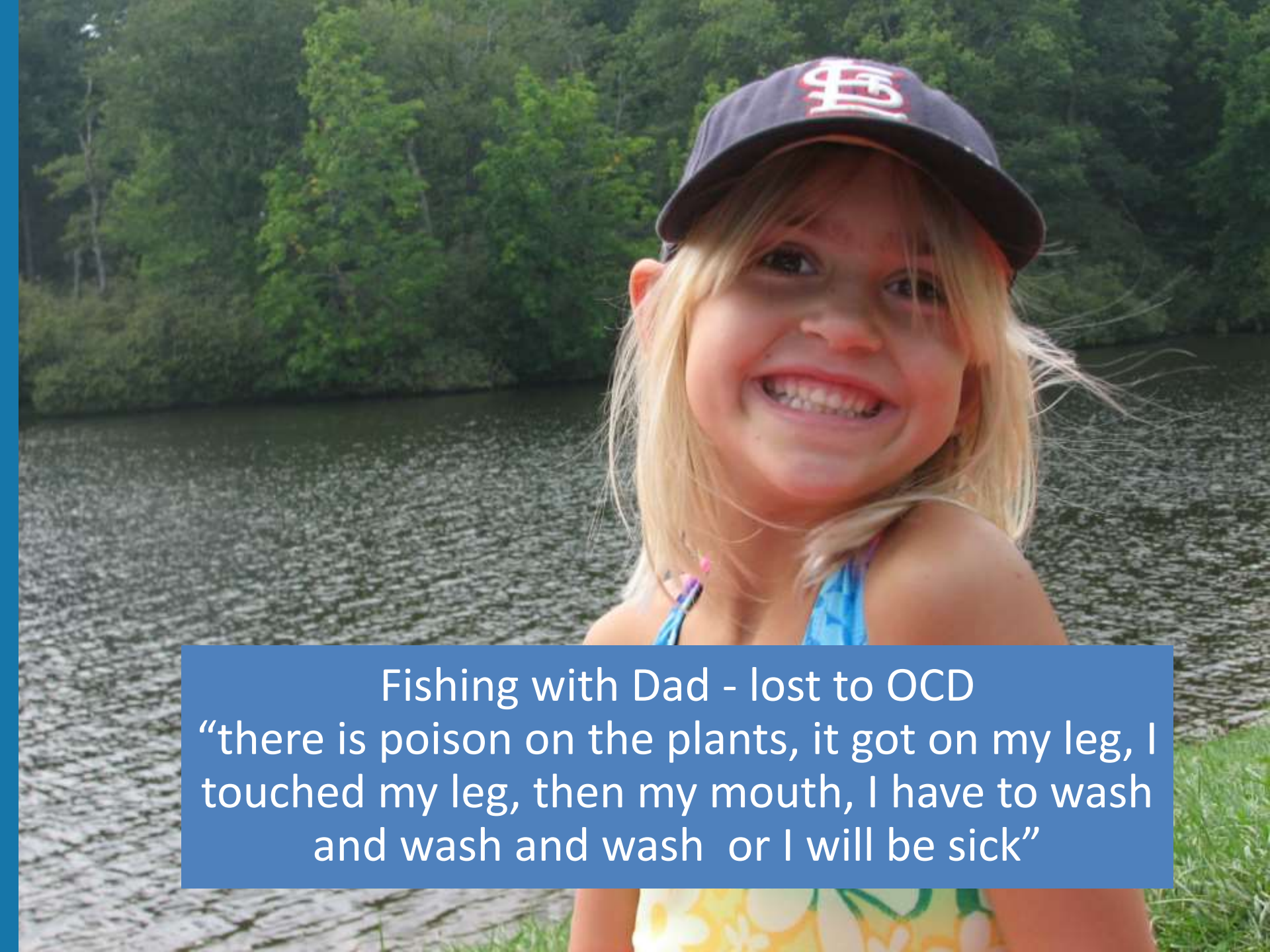
**2018 NC Psychiatric Association Annual Meeting
September 29, 2018**

Susan Boaz, MBA

**President, Board of Directors, International OCD Foundation (IOCDF)
Executive Director, PANDAS Physician's Network (PPN)**

A young girl with blonde hair, wearing a pink dress with large pink polka dots, stands barefoot on a concrete sidewalk. She is smiling and has her right arm raised high. The background consists of a green lawn, a brick wall with a white downspout, and some dark green shrubbery.

Lost to OCD and unable to eat – Age 3



Fishing with Dad - lost to OCD
“there is poison on the plants, it got on my leg, I touched my leg, then my mouth, I have to wash and wash and wash or I will be sick”

PANDAS Diagnostic Criteria

Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections

1. Presence of OCD and/or tics, particularly multiple, complex or unusual tics
2. Acute onset and episodic (relapsing-remitting) course
3. Association with Group A Streptococcal (GAS) infection
4. Association with Neurological Abnormalities

Age Requirement

- Symptoms of the disorder first become evident between 3 years of age and puberty

PANDAS is a **clinical diagnosis**.

There are **no lab tests** that can diagnose PANDAS.

NIMH 2010 Meeting

A collaborative meeting co-organized by the NIMH and parents with affected children.

July 2010 – Clinicians and researchers re-visited the diagnostic criteria of PANDAS in order to expedite the identification and treatment of affected children.

This resulted in focusing on the clinical presentation. The PANDAS criteria were modified to describe PANS (Pediatric Acute-onset Neuropsychiatric Syndrome).

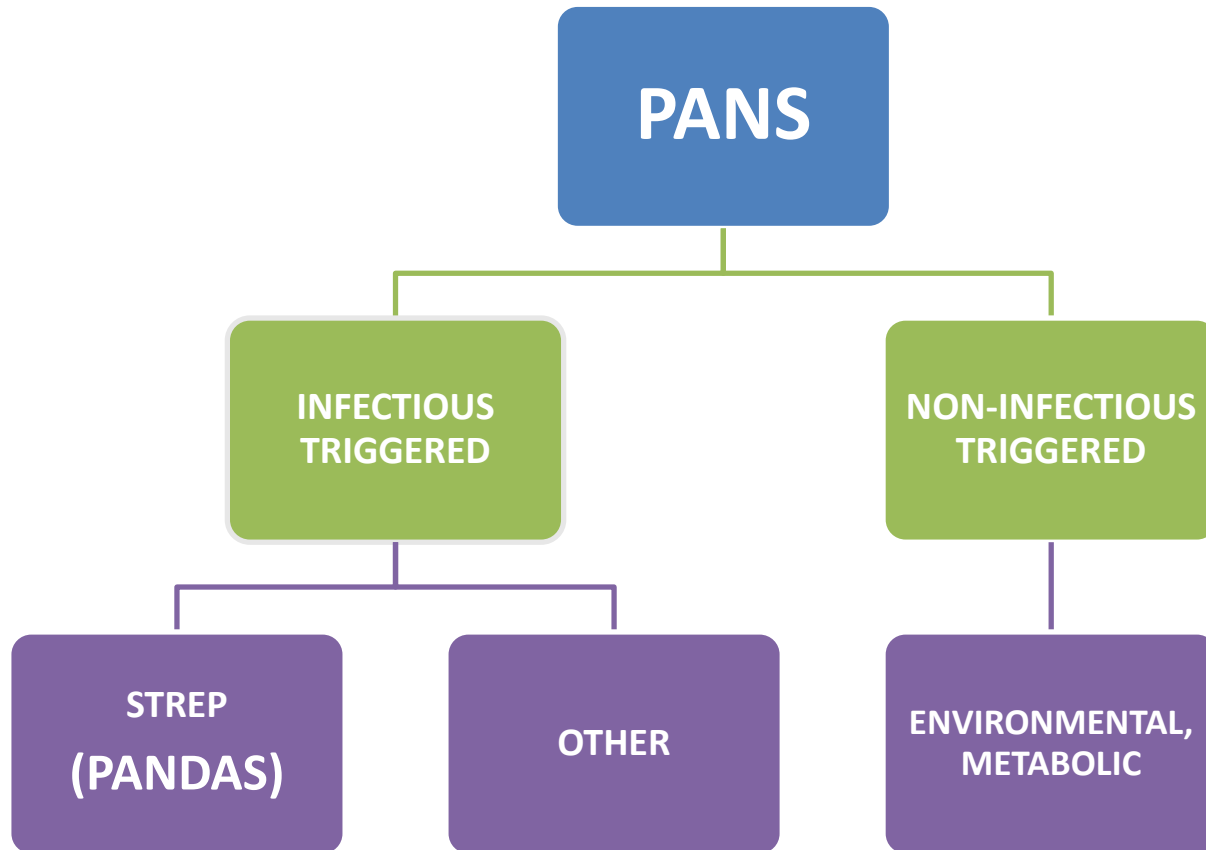


PANS Diagnostic Criteria

Pediatric Acute-onset Neuropsychiatric Syndrome

1. An abrupt, acute, dramatic onset of **obsessive-compulsive disorder (OCD)** or **severely restricted food intake**
2. Concurrent presence of additional neuropsychiatric symptoms with similarly severe and acute onset from at **least 2** of the following categories:
 - Anxiety
 - Emotional Lability and/or Depression
 - Irritability, Aggression, and/or Severe Oppositional Behaviors
 - Behavioral (Developmental) Regression
 - Sudden Deterioration in School Performance
 - Motor or Sensory Abnormalities
 - Somatic Signs and Symptoms, including Sleep Disturbances, Enuresis, or Urinary Frequency
3. **Symptoms are not better explained** by a known neurologic or medical disorder

PANS Hierarchy



Description of Symptoms



OCD

- Presents with a sudden onset typically from mild or no symptoms to debilitating in an abrupt amount of time

Eating Restriction

- Fear of vomiting, sensitivity to taste, smell, and texture, fear food is spoiled, or fear of being poisoned.

Anxiety

- Constant, generalized anxiety or age-inappropriate separation anxiety



Carefree meals – Lost to OCD

“I can’t eat that mom, it has sugar in it, and I will get sick.
I had 10 sugars today. I need to food balance”.

Description of Symptoms



Behavioral Regression

- Baby talk, refusal to carry out age-appropriate grooming activities, tantrums, clinginess, and/or separation anxiety.

Sensory Amplification

- Intensely bothered by smells, tastes, sounds, and textures, causing difficulties with daily routines, such as brushing teeth, riding in a car, eating, and dressing.



Playing in the bath – lost to OCD
“If your fingers get wrinkly, you will be old and die”

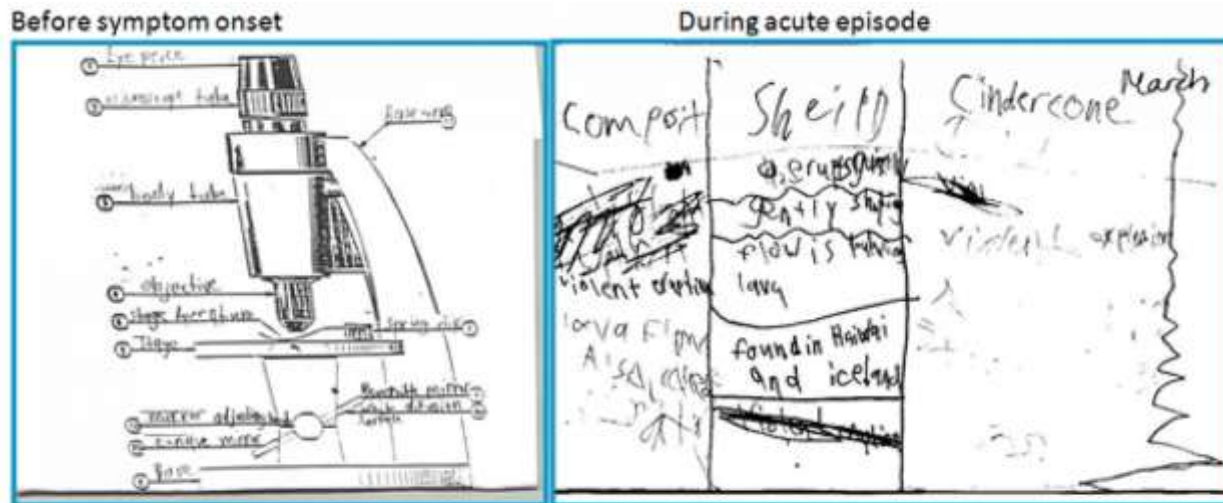
Description of Symptoms

Motor Abnormalities

- Motor and vocal tics, handwriting changes and/or clumsiness

Deterioration in School Performance

- Impairments on a visual-spatial recall test, on measures of executive function, and on a dexterity test.
- Decreased processing speed, memory issues, and/or difficulty in math and calculation.





Cartwheels in the Ocean – lost to OCD
“There are shrimp and bugs in the water – billions and billions that you can not see and they will make me sick”

Description of Symptoms

Mood Disorder

- Depression, mania, irritability, hypersexuality, emotional lability, and rage
- Moods may change from happy to sad to angry in moments.
- Reactive rage

Urinary Symptoms

- Polyuria, frequent urges to urinate, and/or day and night secondary enuresis.
- Urinary symptoms are not due to UTI, anxiety or OCD type worries.

Sleep Disturbances

- initial and middle insomnia, REM behavior disorder, parasomnias, and/or sleep phase shifting.

Red Flags of Possible PANDAS:

Strep (in parents and siblings, as well as patient) followed by:

- “Behavioral disorder”
- OCD
- Other psychiatric diagnoses.

Laughter – lost to OCD
“I can’t laugh mom, my head is too full of worry”



Consensus Statement on Diagnosing PANS Patients

The PANS/PANDAS Research Consortium, in conjunction with the National Institute of Mental Health (NIMH), issued a consensus statement regarding diagnosing PANS/PANDAS in the 2015 edition of the *Journal of Child and Adolescent Psychopharmacology*.

Access the publications at www.pandasppn.org/jcap2015.

JOURNAL OF CHILD AND ADOLESCENT PSYCHOPHARMACOLOGY
Volume 25, Number 1, 2015
Mary Ann Liebert, Inc.
Pp. 3–13
DOI: 10.1089/jcap.2014.0084

Consensus Statement

Clinical Evaluation of Youth with Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS): Recommendations from the 2013 PANS Consensus Conference

Kiki Chang, MD^{1,*}, Jennifer Frankovich, MD^{2,*}, Michael Cooperstock, MD, MPH³, Madeleine W. Cunningham, PhD⁴, M. Elizabeth Latimer, MD⁵, Tanya K. Murphy, MD⁶, Mark Pasternack, MD⁷, Margo Thienemann, MD⁸, Kyle Williams, MD⁹, Jolan Walter, MD¹⁰, and Susan E. Swedo, MD¹¹; From the PANS Collaborative Consortium

Abstract

On May 23 and 24, 2013, the First PANS Consensus Conference was convened at Stanford University, calling together a geographically diverse group of clinicians and researchers from complementary fields of pediatrics: General and developmental pediatrics, infectious diseases, immunology, rheumatology, neurology, and child psychiatry. Participants were academicians with clinical and research interests in pediatric autoimmune neuropsychiatric disorder associated with streptococcus (PANDAS) in youth, and the larger category of pediatric acute-onset neuropsychiatric syndrome (PANS). The goals were to clarify the diagnostic boundaries of PANS, to develop systematic strategies for evaluation of suspected PANS cases, and to set forth the most urgently needed studies in this field. Presented here is a consensus statement proposing recommendations for the diagnostic evaluation of youth presenting with PANS.

Why Early Diagnosis and Intervention is Key

School disruption

Family disruption

- Impact on siblings
- High Caregiver Burden

A median score of 37 was received on the Caregiver Burden Inventory assessment indicating a high burden.

Farmer C, et al. Psychometric Evaluation of the Caregiver Burden Inventory in Children and Adolescents With PANS. *Journal of Pediatric Psychology*. 2018;43(7):749-757.
doi:10.1093/jpepsy/jsy014.

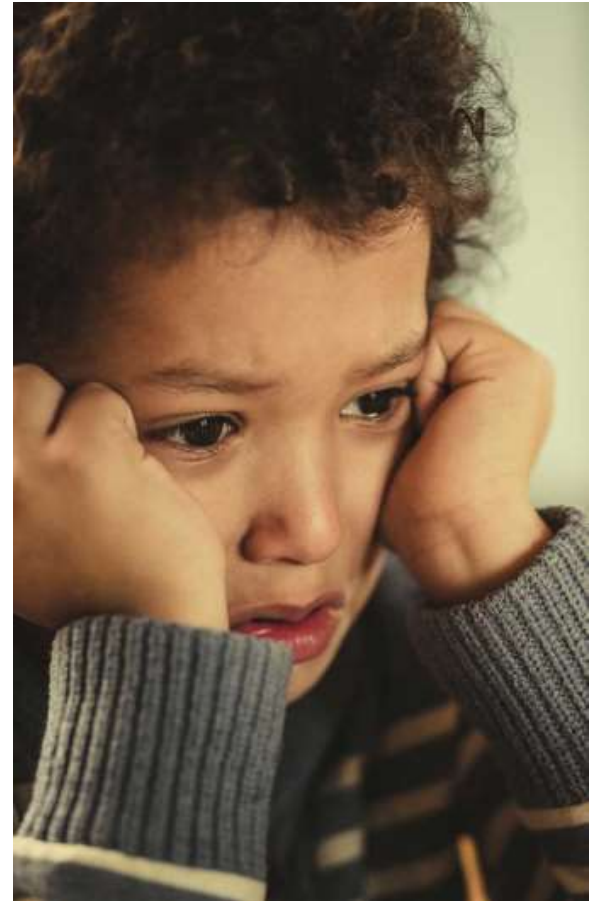


Why Early Diagnosis and Intervention is Key

Psychiatric hospitalization

Evolution of disease into a chronic state

Frankovich Jennifer, et al. Journal of Child and Adolescent Psychopharmacology. July 2017.
<http://doi.org/10.1089/cap.2016.0148>



Why Early Diagnosis and Intervention is Key

Suicidal ideation

Risk of starvation in cases of severe food restriction



PANDAS/PANS Clinical Management Recommendations

Three sets of treatment guidelines were published by the PANS/PANDAS Research Consortium in the 2017 *Journal of Child and Adolescent Psychopharmacology*.

The guidelines address:

1. Antimicrobials and secondary prophylaxis
2. Immunomodulating therapies based on symptom severity
3. Management of symptoms while simultaneously addressing the instigating processes (which includes infections and inflammatory disease)

Access the publications at
www.pandasppn.org/jcap2017.



PANDAS PHYSICIANS NETWORK (PPN)
www.pandasppn.org

Megan – Free
of Severe OCD

One month
after starting
antibiotic
treatment, 75%
remission



Is it OCD or is it PANS/PANDAS?

Overlap between Psychiatric and Autoimmune Brain Disorders

What families often hear: “You treat OCD the same, no matter what causes it”

1. If there is an abrupt, acute, dramatic onset of **obsessive-compulsive disorder (OCD) or severely restricted food intake**, consider PANDAS/PANS and start appropriate treatment
2. **Exposure and Ritual Prevention (ERP)** is an appropriate treatment for all patients with OCD, even PANDAS/PANS patients. ERP may need to be started after the severe PANS crisis has remitted
3. SSRI's can be used successfully with PANDAS/PANS patients (go slow & start low)

Also consider appropriate treatment and provide tools for co-occurring challenges, such as Sensory Integration Issues, ADHD, Separation Anxiety

PANS/PANDAS Advocacy

Parents, Researchers and Physicians Join Together

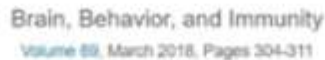


“Patient and parent advocacy groups have been instrumental in bringing these disorders to the attention of both clinicians and researchers. They have worked tirelessly to educate primary care providers, while simultaneously raising funds for pivotal research studies. Most importantly, the advocacy groups have provided support to families in crisis – providing referrals and resources in some cases, and compassionate hands-on care in others.

On a personal note, I am deeply grateful to parents in the IOCDF, PANDAS Physicians Network, PANDAS Network, AE Alliance and other organizations for their support and encouragement; without it, I don’t think I would have been able to continue in the field”.

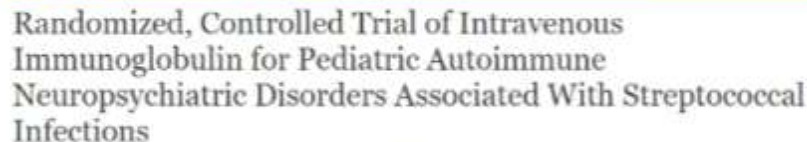
Dr. Sue Swedo
Senior Investigator, Section on Behavioral Pediatrics (SBP)
NIMH

PUBLICATIONS FEATURING PANDAS/PANS RESEARCH



Differential binding of antibodies in PANDAS patients to cholinergic interneurons in the striatum

Luciana R. Frick ^{a,†}, Maoriviani Rapanelli ^{a,†}, Kantiya Jivtachonthong ^a, Paul Grant ^b, James F. Leckman ^{a,‡},
Susan Swedo ^a, Kyle Williams ^{a,‡,§,¶,||}, Christopher Pittenger ^{a,*,‡,§,¶,||}



Kyra A. Williams, MD, PhD, Susan E. Swedo, MD, PhD, Cristian A. Farmer, PhD, Heidi Grantz, LCSW, Paul J. Grant, MD, Precilla D'Souza, CRNP, Rebecca Hammer, MD, Liya Katsovich, MA, Robert A. King, MD, James F. Lockman, MD, PhD



Group A *Streptococcus* intranasal infection promotes CNS infiltration by streptococcal-specific Th17 cells

Thamotharampillai Dileepan,¹ Erica B. Smith,² Daniel Knowland,² Martin Hsu,² Maryann Platt,² Peter Bittner-Eddy,¹ Brenda Cohen,¹ Peter Southern,¹ Elizabeth Latimer,⁴ Earl Harley,⁴ Britan Agalliu,^{1,3} and P. Patrick Cleary¹

**American Society for Microbiology:
Genome Announcements**

PANS/PANDAS Advocacy

Parents, Researchers and Physicians Join Together



“Through engaging and funding clinician scientists and basic scientists, parent-advocates are instrumental in helping to advance clinical care and research in those diseases which are ignored by our current medical system and research establishments. PPN is an excellent example of this.

PPN has funded a research assistant in our clinic for 3 years, allowing us to collect data and clinical samples on over 300 patients. The creation of this biorepository has led to basic science collaborations and several fundamental discoveries”.

Jennifer Frankovich, MDMS
Clinical Associate Professor
Pediatric Rheumatology
Stanford University
Co-Director, Stanford PANS Clinic
Director, Stanford PANS research program

PANDAS Physicians Network

Access diagnostic and therapeutic guidelines at www.pandasppn.org.

Contact PPN at support@pandasppn.org.



Physician Education and Communication

- Distribution of the *Journal of Child and Adolescent Psychopharmacology*
- Sponsoring CME credits at Columbia University Medical Center conference
- Publication of *Seeing Your First Child with PANDAS/PANS*
- Development of CME webinar
- PPN Email Group allows approved members access to an email group to facilitate peer communication



PANDAS Physicians Network

Access diagnostic and therapeutic guidelines at www.pandasppn.org.

Contact PPN at support@pandasppn.org.



Outreach to Medical Community

- Exhibiting at medical specialty conference, including the American Academy of Pediatrics
- Educational ads in physician focused publications, such as *AAP Pediatrics*



PANDAS Physicians Network

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Patient Resource Development

- PPN Practitioner Directory
- National resource webpage
- Supportive resources
- Family oriented handouts

PPN's 2018 Reach

- **165,000** webpage views (Jan-Sept 2018)
- **85%** increase in social media reach
- **57%** increase in physician/medical professional memberships



PPN PRACTITIONER DIRECTORY

Find Locations Near:

Street: City: State:

Zip:

Select a distance: 100 mi ▼

Parent Advocacy

Supporting families while they navigate PANDAS/PANS. legislative actions, and insurance coverage initiatives



**Northwestern
PANDAS/PANS
Network**



**NEW ENGLAND
PANS/PANDAS
ASSOCIATION**



Public Health Advisory Committees have been introduced or established in:

- Arizona
- Connecticut
- Illinois
- Minnesota
- New York
- Pennsylvania
- Virginia
- Wisconsin

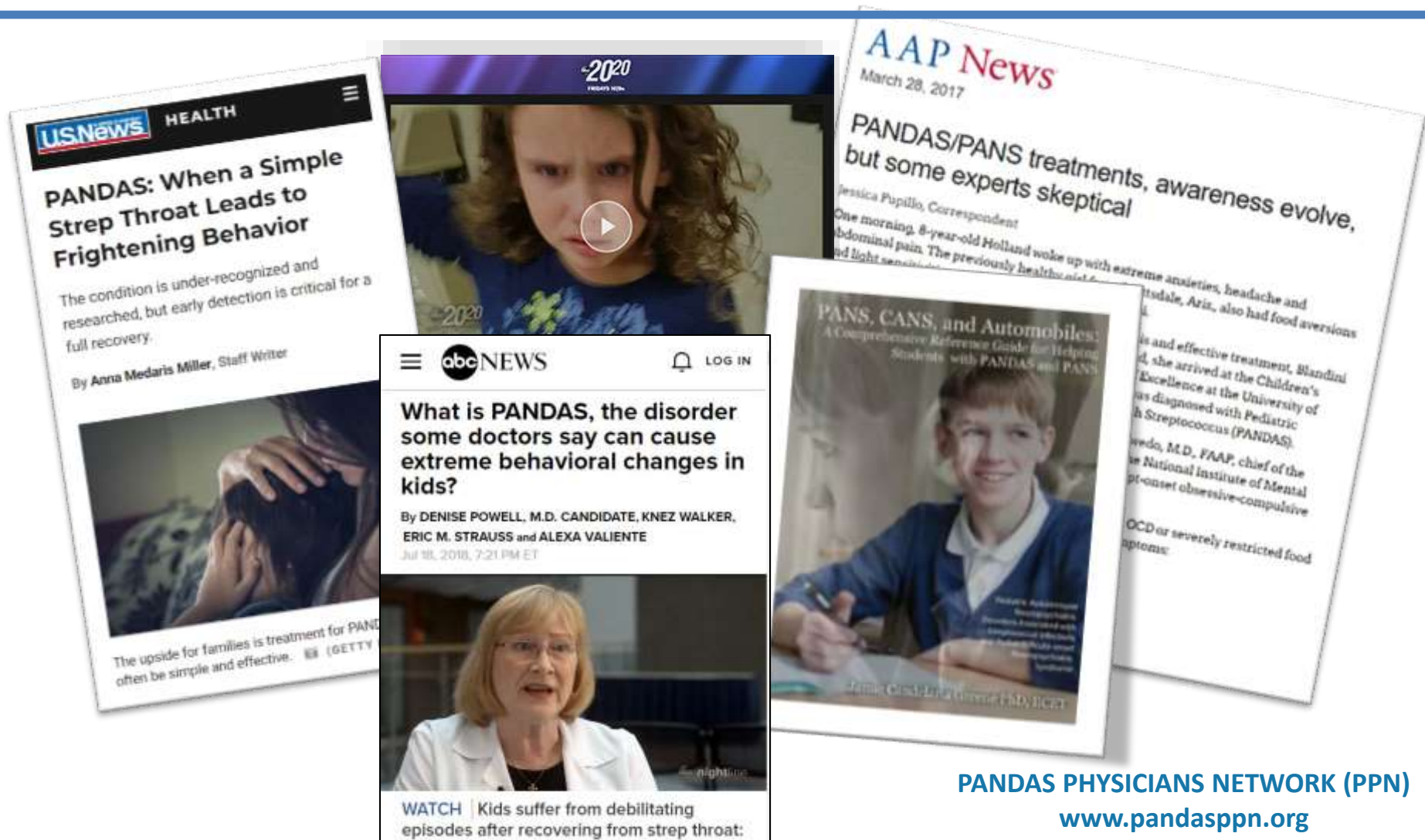
Insurance legislation has been passed in:

- Illinois

PANDAS PHYSICIANS NETWORK (PPN)
www.pandasppn.org

Public Interest

Parent Advocacy has resulted in PANDAS/PANS being recently featured on 20/20, ABC News, and Nightline.



Advocacy creates Public Interest

Parent Advocates have published books and documentaries

UNSTUCK: an OCD kids movie

When your brain is the problem how do you fix it?

To explain what OCD is, and what it isn't, this award-winning short film focuses on an unlikely group of experts: kids.



young people
with an adult-sized problem



Copyrighted Material
"This stirring account of a mother's determination and a boy's astonishing bravery makes you want to stand up and cheer."
—Booklist

Beth Alison Maloney

saving
sammy

A Mother's Fight to Cure Her Son's OCD



In A Pickle Over
PANDAS

Pediatric
Autoimmune
Neurology (PANDAS)
Disorder
Associated with
Streptococcal



written by
Melanie S. Weiss, R.N.

illustrated by
Thomas Barnett

PANS Research Consortium

Founded in 2013 – Advocacy by Researchers and Physicians

The PANS Research Consortium consists of the National Institute of Mental Health (NIMH) in addition to over 30 experts from the fields of pediatrics, infectious diseases, immunology, rheumatology, neurology, and child psychiatry.

The consortium has collaborated to develop and publish evaluation guidelines for PANDAS/PANS along with updated treatment recommendations.

Examples of academic institution represented:

Harvard, Yale, Stanford, Columbia, Georgetown

About the International OCD Foundation

The International OCD Foundation is a donor-supported nonprofit organization. Founded in 1986 by a small group of individuals with OCD, the Foundation has grown into an international membership-based organization serving a broad community of individuals with OCD and related disorders, their family members and loved ones, and mental health professionals and researchers. We have affiliates in 24 states and territories in the US, in addition to partnerships with other OCD organizations around the world.



The International OCD Foundation Supports Research and Education about PANDAS & PANS

[Who We Are](#)[About OCD](#)[For Parents](#)[For Kids](#)[For Professionals](#)[IOCDF Ho](#)[Find Help](#)[Learn More About OCD](#)

If you have a patient presenting with repetitive behaviors and chronic anxiety, it may be obsessive compulsive disorder (OCD) or it may be a subtype of OCD: *Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcus* (PANDAS)/ *Pediatric Acute-Onset Neuropsychiatric Syndrome* (PANS). There are recognizable differences between these conditions:

	Pediatric OCD	PANDAS/PANS
AGE	Typically see first onset between 8–12 years old.	Typically affects children between 4–14 years old.
TIMELINE	Subclinical symptoms become gradually more severe over time.	Acute, dramatic onset of symptoms.
SYMPTOMS	Experience a wide range of symptoms, cycling between obsessions that cause anxiety and compulsions to reduce it. Common obsessions may include fears of contamination, pathological doubt, unwanted thoughts and/or images of an aggressive, religious, or sexual nature, or the need for symmetry. Common compulsions may involve excessive checking, washing and/or cleaning, or reassurance seeking, counting, ordering, or arranging things.	Sudden, rapid-onset of obsessive-compulsive behavior, as well as possible movement and behavioral abnormalities, including: <ul style="list-style-type: none">▪ Severe separation anxiety▪ Anorexia or disordered eating▪ Urinary frequency▪ Tics and/or purposeless motor movements

IOCDF – Behavioral Therapy Training Institute (BTTI)

IOCDF Training Institute

- These trainings are designed to update mental health professionals in effective treatments for OCD.
- Trainings range from introductory to advanced
- Trainings are available online and in person.
- Please visit:
www.iocdf.org/professionals/training-institute for more information.

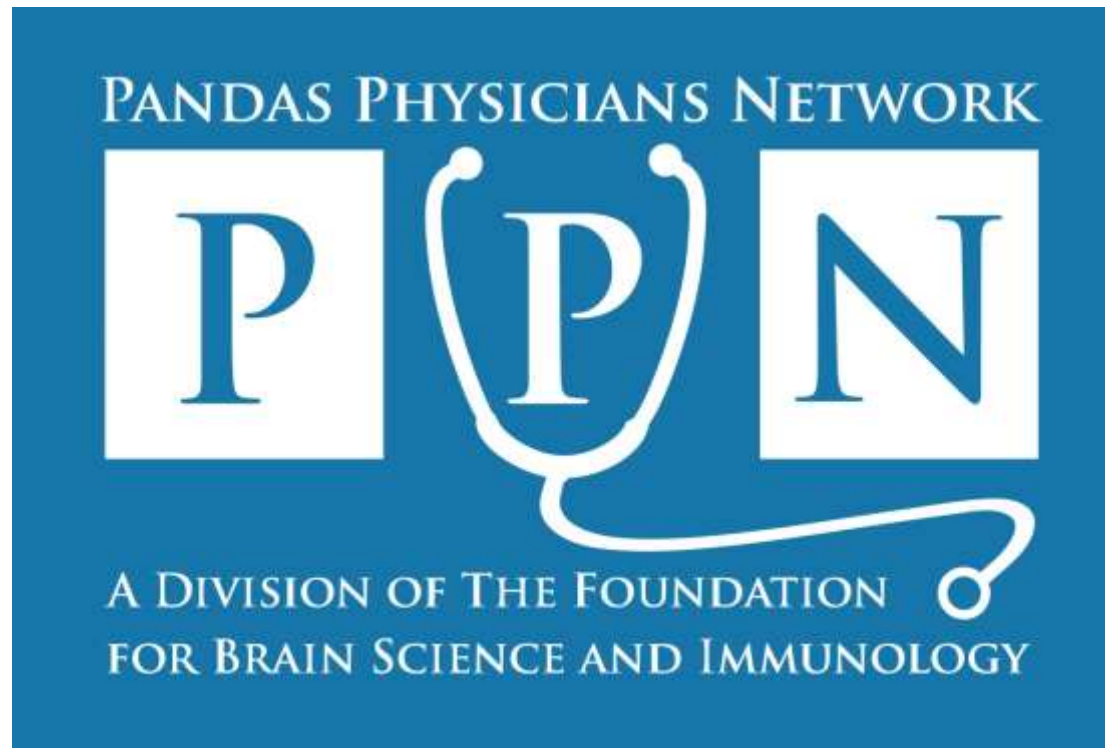




Megan – 10 years later
The combination of ABX (PANDAS) and ERP
(OCD) give her a full life

Joyous, confident, and on her way to college

**Access diagnostic and therapeutic
guidelines at www.PANDASPPN.org.**



The Power of Turning Adversity into Advocacy



“It is one of the beautiful compensations of life that no man can sincerely help another without helping himself.”

- Ralph Waldo Emerson

Why Adversity-Driven Advocacy Works



By being of **service** to others with adversities similar to our own, we apply our **empathy** in a way that provides a powerful sense of **purpose** and fuels our **resilience**.

What the Experts Say...



“We have parts of our brain and nervous system linked to dopamine and oxytocin circuits that are activated when we give and serve. So when we give hope to others ... we derive very deep pleasure—pleasure that is as strong as when we receive hope, ourselves.”

- Dacher Keltner, Ph.D.

Author, *“Born to be Good: The Science of a Meaningful Life”*